

**A Study of the Relationships between Post Traumatic Stress
Disorder, Significant Other Burden and Psychological Distress.**

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Contents

List of Tables	Page
Table 1: Demographic Characteristics, Relationship and Occupational Status and Previous Psychiatric Treatment for Patients and Significant Others	61
Table 2: Medians and Inter-quartile Range for Key Measures and Subscales for Patients and Significant Others	65
Table 3: Two-Tailed Spearman Correlations of Key Measures and Subscales for 25 Patients and Significant Others	66
List of Figures	
Fig 1. Numbers of Patients Reporting Each of Eight Categories of Traumatic Experiences	63

Chapters	Page
1.0 Introduction	1
1.1 Post Traumatic Stress Disorder	1
1.1.1 Definition of Post Traumatic Stress Disorder	1
1.1.2 History of Post Traumatic Stress Disorder	3
1.1.3 Prevalence of Post Traumatic Stress Disorder	5
1.1.4 Predictors of Post Traumatic Stress Disorder	8
1.1.5 Treatment of PTSD	11
1.1.6 Positive Consequences of PTSD	13
1.1.7 The Effects of PTSD on Others	16
1.2 Burden	32
1.2.1 Definition of Burden	32
1.2.2 The Relation of Burden to Psychiatric Illness	32
1.2.3 Burden Related to Post Traumatic Stress Disorder	35
1.3 Anxiety	38
1.3.1 Definition of Anxiety	38
1.4 Depression	38
1.4.1 Definition of Depression	38
1.5 Social Support	39
1.5.1 Definition of Social Support	39
1.5.2 The Role of Social Support	40
1.5.3 Social Support and PTSD	40
1.5.4 Social Support and Other Psychological Problems	41
1.6 Positive Aspects of Caregiving	42
1.7 Study Rationale	45
1.8 Aims and Hypotheses	47
2.0 Method	49
2.1 Ethical Issues	49
2.2 Participants	49
2.2.1 Recruitment	49
2.3 Design	50
2.3.1 Postal Surveys	51
2.4 Measures	52
2.5 Procedure	57
2.6 Inclusion Criteria	58
2.7 Power	59
3.0 Results	60
3.1 Background Information	60
3.2 Study Response Rates	61
3.3 Missing Data	61
3.4 Statistical Methodology	62
3.5 Demographics	62
3.5.1 Patients	62
3.5.2 Significant Others	64
3.6 Exploration of Hypotheses	66
3.7 Additional Findings	69
3.8 Qualitative Information from Significant Others	70

4.0	Discussion	72
4.1	Overview	72
4.2	Summary of Key Findings	72
4.3	Examination of Hypotheses	73
4.4	Examination of Additional Findings	85
4.5	Preliminary Analysis of Themes from Open-Ended Questions	87
4.6	Implications for the NHS	90
4.7	Statistical Considerations	92
4.7.1	Effect Size	93
4.7.2	Post Hoc Power	94
4.8	Strengths	95
4.9	Limitations	96
4.9.1	Slow Recruitment	96
4.9.2	Sample Size	98
4.9.3	Generalisability	99
4.9.4	Design Considerations	100
4.10	Interpretation of Findings and Future Research	104
4.11	Conclusion	108
5.0	References	110

Appendices

1	Diagnostic Criteria for Post Traumatic Stress Disorder
2	Diagnostic Criteria for Acute Stress Disorder
3	Letter Confirming Ethical Approval
4	Patient Information Sheet
5	Patient Demographics Questionnaire
6	Information Sheet for Significant Others
7	Cover Letter to Significant Other
8	Demographics Questionnaire for Significant Others
9	Hospital Anxiety and Depression Scale
10	MSPSS Social Support Scale
11	Burden Inventory
12	Impact of Event Scale – Revised
13	Patient Consent Form
14	Significant Other Consent Form

Abstract

Background Previous studies have suggested that PTSD is related to burden and psychological distress in the wives of combat veterans with PTSD. However, these links have not been studied in non veterans with PTSD. This study recruited NHS patients who were undergoing treatment for PTSD, along with their 'significant others', including partners, other family members and close friends. The links between levels of PTSD and the effects of PTSD on the psychological functioning and perceived burden in significant others were examined.

Method Two groups of participants were assessed. The first comprised 25 patients and the second comprised 25 nominated significant others. Patients completed a measure of trauma (IES-R) and significant others completed measures of anxiety and depression (HADS), burden (BI) and social support (MSPSS).

Results Spearman correlations revealed that the IES-R was not significantly associated with the BI and no statistically significant correlations were found between the IES-R and the anxiety and depression subscales of the HADS, or between the BI and the anxiety and depression subscales of the HADS. Furthermore, the MSPSS and BI were not significantly correlated.

Conclusion In contrast to previous research, there were no statistically significant relationships between levels of PTSD and levels of significant other burden. However, many patients were unable to nominate significant others. Analyses were underpowered; therefore it is not possible to conclude unequivocally that relationships between PTSD and burden do not exist, although it is not possible to draw firm conclusions based on the present data. The present study extends existing knowledge by including patients from an NHS setting and their significant others.

1.0 Introduction

1.1 Post Traumatic Stress Disorder

1.1.1 Definition of Post Traumatic Stress Disorder

Post traumatic stress disorder (PTSD) is only one of many possible reactions to experiencing a traumatic event. However, the present study concerns the effects of PTSD, which is a debilitating condition and affects the lives of 5 per cent of males and 10 per cent of females in the general population (Iribarren *et al.*, 2005). In addition, almost one third of people with a history of PTSD fail to recover, even after a lengthy period (Kessler *et al.*, 1995). Two main systems are used for the classification of PTSD. These are the International Classification of Diseases (ICD) (World Health Organisation, 2007) and the Diagnostic and Statistical Manual (DSM) (American Psychiatric Association, 2000). Both the ICD and the DSM are similar. What will now follow is based on the classification of PTSD using the DSM fourth edition text revision (DSM-IV-TR).

The following difficulties are likely in adults with PTSD: experiencing recurrent and intrusive distressing recollections of the event, including images thoughts, or perceptions, recurrent distressing dreams of the event, or acting or feeling as if the traumatic event were recurring. This can include a sense of reliving the experience, illusions, hallucinations and dissociative flashback episodes.

People may also display persistent avoidance of stimuli associated with the trauma; for example, avoiding thoughts, feelings, or conversations associated with the trauma and avoiding activities, places, or people that arouse recollections of the trauma.

They may also experience difficulty falling or staying asleep, irritability or outbursts of anger, difficulty concentrating, hypervigilance, or an exaggerated startle response (see appendix 1 for the complete DSM-IV-TR criteria).

Van der Kolk *et al.* (2007) noted a number of limitations with using the DSM IV criteria for the diagnosis of PTSD. For example, they argue that by restricting the diagnosis to essential features (i.e. only those necessary for a diagnosis), this excludes many of the features of PTSD that may have clinical relevance. They also note that this can lead to two main problems: either a PTSD diagnosis may be missed due to other features being more prominent, or other features may be overlooked due to the presence of PTSD.

In addition to the DSM IV criteria for PTSD, PTSD has been categorised into two types (Terr, 1991). Type 1 PTSD (which fits the definition of PTSD currently found in DSM-IV) is characterised as less severe in complexity, often following single event traumatic experiences, and shows the classic symptoms of intrusion and re-experiencing that are described in DSM-IV. Type 2 PTSD describes sustained or repeated traumas, which are greater in complexity. Memories of the trauma are likely to be less detailed, and Type 2 traumas are commonly associated with intentional human acts, such as sexual abuse or combat exposure. Terr (1991) suggests that unlike the emotional responses in Type 1 PTSD, the emotions elicited in Type 2 PTSD include an absence of feeling, a sense of rage and unremitting sadness. In

addition, negative changes in personality are consistent with the type of prolonged exposure to trauma that is characteristic of Type 2 PTSD (Herman, 1992) and due to subsequent changes in personality, people with Type 2 PTSD commonly risk being misdiagnosed as having personality disorders (Herman, 1992). Type 2 trauma is also referred to as 'complex' PTSD, which is currently covered by DSM-IV under the section 'disorders of extreme stress not otherwise specified'. However, it should be noted that the categories of Type 1 and 2 trauma are not DSM-IV categories. Herman (2001) notes that there is a debate over the use of the term 'complex' or Type 2 trauma, and argues that the current DSM-IV criteria do not adequately describe the complex presentations that are commonly found in people who have experienced repeated or prolonged traumatic experiences.

1.1.2 History of Post Traumatic Stress Disorder

According to Yule *et al.* (1999) reports of traumatic stress have been recorded over the past four hundred years. They note that William Shakespeare wrote about reactions to acute stress in many of his plays. In addition, in Victorian times, the term 'railway spine' was used to describe the psychological consequences of experiencing major transportation disasters, such as rail crashes. It was believed that actual damage to the spine and the central nervous system resulted in psychological responses that were out of proportion to the actual accident (Erichsen, 1866; Trimble, 1981).

A number of other terms have been used to describe reactions to traumatic incidents. These have included nervous shock (Page, 1885), fright neurosis (Kraepelin, 1886), traumatic neurosis (Oppenheim, 1892), and anxiety neurosis (Freud, 1894). The next significant term that was used to describe the effects of traumatic stress was 'shell

shock' (Mott, 1919). This term emerged from physicians treating soldiers in the First World War. They reported that soldiers would 'break down' on the battlefield. The response at that time was often to accuse soldiers of cowardice, and those who refused to fight were often executed.

By the beginning of the Second World War a greater understanding of soldiers' reactions to traumatic events was beginning to develop. Kardiner (1941) termed the reaction to traumatic stress as 'post-trauma syndrome', and noted that people with this syndrome had feelings of irritability, outbursts of aggression, exaggerated startle response and fixations on the traumatic event (Yule *et al.*, 1999). Following the Second World War, studies were conducted into the experiences of survivors of the holocaust. A study by Eitinger (1962) found that of 100 survivors whom they interviewed, 85 per cent had symptoms similar to what would now be classed as PTSD.

The next great advance in our understanding of how traumatic events affect people emerged following the end of the Vietnam War, at the time when soldiers were returning to the United States. It was around this time that Horowitz (1975; 1976; 1979) developed his theories for understanding PTSD based on his observations of veterans. He proposed that they would experience intrusive and disturbing thoughts and images and would use avoidance strategies to avoid re-experiencing the traumatic memories. Figley (1978) wrote that one of the legacies of the Vietnam conflict has been the recognition of the syndrome of PTSD. In addition, the current classification of PTSD in DSM-IV has its origins in post-Vietnam North America (Yule *et al.*,

1999). Since the 1970s onwards, the scientific literature on PTSD has developed significantly.

1.1.3 Prevalence of Post Traumatic Stress Disorder

The prevalence rates of PTSD vary depending on the nature and number of traumatic events that have occurred and the number of people who have been exposed to them. In addition, the prevalence of PTSD has been shown to vary between samples, between clinical populations, and in the general population. There are a number of reasons which might account for this, such as sampling methodology, type of trauma, the use of psychometric measures, and diagnostic criteria.

Iribarren *et al.* (2005) reported that in the United States in the late 1990s, five per cent of males and ten per cent of females would meet the criteria for a diagnosis of PTSD. However, they also reported that, during the same period, the prevalence among veterans was 15.2 per cent. Furthermore, Iribarren *et al.* also noted that around 30 per cent of those who had served in recent combat had experienced PTSD. A number of studies have also examined the prevalence rates in professions which are commonly involved with traumatic situations. Ambulance service and fire and rescue service personnel have been shown to have prevalence rates of 18-30 per cent, much higher than the general population (Alexander & Klein, 2001; Wagner *et al.*, 1998). It has been estimated that, in the year 2000, there were five to six million adults living with PTSD in the United States (Iribarren *et al.*, 2005). It has also been suggested that, due to the high levels of global conflict, this figure may rise sharply over the next decade (Iribarren *et al.*, 2005).

Many studies have examined the prevalence rates of PTSD following road traffic accidents (RTAs). Mayou *et al.* (1993) examined admissions to hospital following RTAs and found that following a one year period, 11 per cent met the criteria for a diagnosis of PTSD. In a further similar study, Ehlers *et al.* (1998) assessed people who had been admitted to hospital following an RTA at three and six month follow up. They found that 23 per cent of their sample met the criteria for a diagnosis of PTSD at three month follow up, and 16.5 per cent of the sample met the criteria for PTSD one year after admission. However, a study by Blanchard *et al.* (1994) reported that of those individuals seeking medical help following an RTA, 29 per cent met the criteria for a diagnosis of PTSD. In addition, in a more recent study of the relationship between RTAs and PTSD, Coffey *et al.* (2006) found that of 229 participants in their study, 43 per cent met the criteria for PTSD using psychometric measures of PTSD.

PTSD has also been shown to be common following large scale transport accidents. Yule *et al.* (2000) interviewed 217 adolescents who had been on the cruise ship Jupiter which sank in 1988. They found that eight years after the incident, over 50 per cent of the survivors had gone on to develop PTSD, compared to a control group which had 3.4 per cent prevalence for the same period.

PTSD can also frequently occur following natural disasters. For example, in a study of the victims of a major flood in China, Feng *et al.* (2007) reported that of the 25,000 people interviewed, 9.7 per cent were diagnosed with PTSD. However, they noted that for the participants who had been involved in flash flooding, the rates of PTSD were as high as 24.9 per cent. The prevalence rate of PTSD following earthquakes is also high. Wang *et al.* (2000) found that in a longitudinal study of people living in

northern China, rates of PTSD following earthquakes were 24.2 per cent. Furthermore, studies have shown that immigrants and refugees are significantly more likely to suffer from PTSD than the general population. This is especially the case if refugees have come from countries which are at war, or where there is political unrest (Ozer *et al.*, 2003). A study of Central American refugees, who had fled from political unrest and armed conflict, found that 52 per cent of those interviewed met the criteria for a diagnosis of PTSD (Cervantes *et al.*, 1989).

In the US Epidemiological Catchment Area Study, based on a sample from the general population, it was found that the prevalence rate for PTSD in the general population was 7.8 per cent (10.4 per cent for females and 5 per cent for males) (Kessler *et al.*, 1995). These are consistent with the findings reported by Iribarren *et al.* (2005). As can be seen this is clearly lower than the rates in more clinically defined populations, such as those mentioned above. It is also interesting that, although the events noted above can be traumatic, they do not affect everyone who is exposed to them. There are a number of personal and social factors which affect the likelihood of someone developing PTSD, and these will be discussed in section 1.1.4.

It should be highlighted that, although a selection of different traumatised populations are described above, the majority of research on PTSD over the past three decades has emerged from studies on Vietnam War veterans in the United States. This limits the extent to which the findings of such research can be generalised to non-combat veterans in the United States and other countries. Furthermore, when considering how people with PTSD are treated for this disorder, there are likely to be variations in health care provision with patients in the United Kingdom receiving treatment

through National Health Service (NHS) primary care and specialist clinics, as opposed to patients in the United States who are often seen through Veteran specific treatment programmes.

1.1.4 Predictors of Post Traumatic Stress Disorder

PTSD has been conceptualised as a normal response to an overwhelming psychological trauma (Brewin *et al.*, 2000). However, over the past three decades, a number of factors have been shown to be related to a person's likelihood of experiencing, or continuing to experience, PTSD.

Ozer *et al.* (2003) conducted a meta-analysis of 68 published studies. Their analysis examined seven different predictors that were associated with PTSD. These were prior trauma, prior psychological adjustment, family history of psychopathology, perceived life threat during the trauma, post-trauma social support, peri-traumatic emotional responses, and peri-traumatic dissociation. Their analysis showed that all of the above factors were significant predictors of PTSD; however, they noted that peri-traumatic dissociation was the largest predictor of PTSD and concluded that it is the 'in the moment' peri-traumatic cognitive processes, rather than pre PTSD characteristics, that are the greatest predictors of PTSD. Ozer *et al.* (2003) also reported that the relationship between peri-traumatic dissociation and PTSD was highest in studies where six months to three years had elapsed before assessment. They found that the severity of the response to the trauma may have a significant effect on the level of peri-traumatic dissociation. The second greatest predictor of PTSD in the Ozer *et al.* study was perceived social support. Their analysis showed a negative relationship between perceived social support and PTSD, i.e. the less social

support, the more likelihood of developing PTSD. It was also observed that poor social support emerged as a stronger predictor of PTSD in studies where the traumatic event had occurred three years prior to the research. Consequently, Ozer *et al.* hypothesised that the positive effects of social support may be cumulative over time.

In a meta-analysis of the predictors of PTSD, Brewin *et al.* (2000) examined 77 studies of PTSD, which included military and civilian populations. They analysed 14 risk factors that predicted PTSD, which were gender (females at greater risk than males), younger age, low socioeconomic status, lack of education, low intelligence, ethnic minority status, psychiatric history, childhood abuse, other previous traumas, other adverse childhood events, family psychiatric history, trauma severity, lack of social support, and life stress. All of the above factors predicted PTSD to some degree, with poor social support being the strongest predictor of PTSD ($r = .40$) (cf. Ozer *et al.*, 2003). However, Brewin *et al.* suggest that the predictors above should be viewed with some caution, as their samples were heterogeneous and for some populations, factors such as age at trauma, gender and race were not found to be risk factors at all.

When examining further risk factors related to the development and maintenance of PTSD, Kaniasty and Norris (2008) noted a number of factors which may affect the likelihood of a person receiving poor social support. These included a patient's diminished interest in interpersonal activities, unremitting feelings of detachment and estrangement from others, and angry outbursts. They also suggest that the negative appraisals and cognitions experienced by people with PTSD could lead them to depreciate the supportive efforts of others, which would mean that support could diminish further. Kaniasty and Norris noted that there are two different processes

which may explain why a person receives or does not receive social support. They term the first process 'social selection', which proposes that the presence of PTSD results in a lowering of social status or failure to escape from low socioeconomic conditions. The second process is termed 'social causation', which proposes that environmental adversity, disadvantage and stress associated with poor socioeconomic conditions contribute to the onset of PTSD. Kaniasty and Norris found that in the first 6-12 months the social causation process explained the levels of social support that a person with PTSD received, whereas at 18-24 months the social selection process explained the levels of social support that a person received was more strongly predictive of received social support.

Emotional factors are also important in the prediction of PTSD. For example, a study by Andrews *et al.* (2000) found that shame and anger with others were significant correlates of PTSD. In addition, it has also been found that levels of dissociation which occur during the trauma can be predictive of PTSD (Shalev *et al.*, 1996). Furthermore, acute stress disorder (see appendix 2 for DSM-IV-TR definition) has also been shown to predict PTSD in prospective studies (e.g. Brewin, *et al.*, 1999).

Brewin *et al.* (2000) note that there are a number of methodological and research limitations in the literature relating to the risk factors for PTSD. They argue that there has been little consistency in the risk factors that have been investigated. Furthermore, there has been a lack of consistency in the measures that are used to assess PTSD and other risk factors. In addition, some studies include participants who have had a lifetime diagnosis, whereas other studies included participants with a current

diagnosis. It is therefore likely that the predictors that emerge from these two time scales of PTSD will be somewhat different.

When reviewing articles for inclusion in their meta-analysis, Brewin and colleagues noted that a number of different measures, such as the Mississippi Scale for Combat-Related Stress Disorder (Keane *et al.*, 1988), the Impact of Events Scale-Revised (Weiss & Marmar, 1996) and the Posttraumatic Symptom Scale (Foa *et al.*, 1993) had been used to measure diverse PTSD symptoms related to risk factors. They suggested that this process was acceptable; however, they reported that a number of studies had used the Impact of Events Scale (IES)(Horowitz *et al.*, 1979), which is problematic as it does not measure arousal symptoms. Furthermore, it was found that studies rarely reported the length of time that a person's symptoms had been present (Brewin *et al.*, 2000). Some large epidemiological studies (e.g. Breslau *et al.*, 1991) have reported the effects of trauma, but have not differentiated between trauma that occurred in childhood and trauma that occurred in adulthood. Moreover, there are few prospective studies which look at participants before they develop PTSD. Brewin and colleagues also explained that retrospective designs were more likely to have focused on military samples, and, in addition, were more likely to have been conducted with all male participants.

1.1.5 Treatment of PTSD

The National Institute for Health and Clinical Excellence (NICE; 2005) guidelines have suggested that trauma-focused cognitive behavioural therapy (CBT) or eye movement desensitisation and reprocessing (EMDR) therapy should be offered to people with PTSD.

Cognitive Behavioural Therapy (CBT)

There are a number of different components in the CBT treatment of PTSD. These include: psychoeducation, exposure, cognitive restructuring and anxiety management (Harvey *et al.*, 2003). Harvey *et al.* (2003) reviewed the efficacy of CBT for the treatment of a number of different traumatic experiences. These included assault, terrorism, road traffic accidents, combat exposure, and childhood abuse. They concluded that there was strong support for the efficacy of CBT for PTSD across a variety of different types of traumatic events. It has also been shown that in a sample of 57 motor vehicle accident survivors, improvements made following a ten session course of CBT for PTSD remained consistent at twelve month follow-up (Blanchard *et al.*, 2004).

Eye Movement Desensitisation and Reprocessing (EMDR)

EMDR involves the focus of attention on a traumatic memory whilst simultaneously tracking the therapist's finger as it moves across one's visual field (Harvey *et al.*, 2003). A number of reviews of studies have been supportive of the effectiveness of EMDR (e.g. DeBell & Jones, 1997; Shapiro, 1996). A meta-analysis of 34 studies which used EMDR found that EMDR was effective in treating PTSD when compared with no treatment and pretreatment conditions (Davidson & Parker, 2001). In addition, it has been shown that five sessions of EMDR were successful in treating PTSD and treatment effects were maintained at 35-month follow-up (Hogberg *et al.*, 2008). However, when compared with other exposure-based therapies, a review suggested that there were no significant differences in its effectiveness and the eye movements (which are the core process of the therapy) were not a necessary

component in treatment outcome (Davidson & Parker, 2001). Furthermore, when compared with nine sessions of CBT, nine sessions of EMDR were found to be less effective (Deville & Spence, 1999). However, the findings of this study were based on a total sample of 23 participants with only 12 participants in the CBT group and 11 in the EMDR group and a sample size this small is likely to be underpowered when using analyses such as MANOVA. One could therefore conclude that this methodology was not adequate for assessing the relative effectiveness of CBT and EMDR.

1.1.6 Positive Consequences of PTSD

Although the literature on PTSD primarily focuses on the negative aspects of how the disorder affects people's lives, there is a growing literature focusing on the positive outcomes which can occur during a person's experience of trauma. Positive aspects of trauma have been referred to as post-traumatic growth (Zoellner & Maercker, 2006). However, this phenomenon has also been labelled 'adversarial growth', 'benefit finding', 'thriving' and 'flourishing' (Joseph & Linley, 2006). The term posttraumatic growth will be used here. Zoellner & Maercker (2006) state that: 'The term 'posttraumatic' stresses that growth happens in the aftermath of an extremely stressful event (traumatic event), not as the result of any minor stress or as part of the developmental process...there is something positively new which signifies a kind of additional benefit compared to pre-crisis level' (p. 628). Examples of post-traumatic growth include an increased appreciation for life, closer intimate relationships, a sense of increased personal strength and positive spiritual changes (Tedeschi *et al.*, 1998). It has been argued that posttraumatic growth is not merely increased wellbeing or decreased levels of distress, rather people can experience both distress and growth

simultaneously (Tedeschi & Calhoun, 2004). Zoellner and Maercker (2006) argue that 'Psychotraumatology has too long focused solely on the detrimental effects of trauma and has, thus, confined the understanding of trauma recovery to a deficit orientated model' (p. 650). They suggest that posttraumatic growth can be viewed as a form of coping which can be used clinically.

In a review of ten cross-sectional studies of the relationships between posttraumatic growth and levels of PTSD symptoms, it was found that there was a lack of systematic relationships. For example, studies found a range of correlations between measures of PTSD and posttraumatic growth, from small negative correlations ($r=-.2$) to small positive correlations ($r=.2$) (Zoellner & Maercker, 2006). However, it is important to note that correlations varying between $r=-.2$ and $r=.2$ may simply represent sampling variability around a 'true' score of $r=.0$. It is interesting to see that there are positive correlations, as such relationships suggest that higher levels of PTSD are associated with higher levels of posttraumatic growth.

A longitudinal study of the relationships between posttraumatic growth and PTSD in the survivors of tornado, mass killings and aviation accidents, found that posttraumatic growth predicted fewer PTSD symptoms three years following the traumatic events. However, it was not predictive of a change in diagnosis (McMillen *et al.*, 1997). It has also been reported that posttraumatic growth is not predictive of long-term improved emotional adjustment (Joseph & Linley, 2006).

Zoellner and Maercker (2006) highlighted that even when researchers were examining the same data, different authors came to different conclusions. For example, it has been reported that posttraumatic growth predicts wellbeing (Affleck & Tennen, 1996),

whereas others have reported that posttraumatic growth is highly limited with regard to its adaptive value (Filipp, 1999).

There are a number of personal factors that can influence posttraumatic growth. For example, people who are optimistic and have high levels of self-esteem are more likely to report posttraumatic growth, compared with those with less optimism and lower self-esteem (Linley & Joseph, 2004). Furthermore, depression was negatively correlated with posttraumatic growth (Frazier *et al*, 2001; Updegraff *et al.*, 2002). Therefore, depression is a factor that may need to be accounted for when attempting to understand the process of posttraumatic growth.

A number of limitations have been reported regarding the conceptualisation and validity of posttraumatic growth (Zoellner & Maercker, 2006). For example, it has been suggested that posttraumatic growth should be regarded as the absence of psychological distress (Zoellner & Maercker). It is also notable that the causes of trauma vary widely and that the different types of traumatic event may have a different impact on levels of posttraumatic growth (when compared with a different type of traumatic event). This is a particular difficulty in the literature, as studies can often include the survivors of a number of different traumatic experiences.

In their review of the literature on posttraumatic growth, Zoellner and Maercker (2006) conclude that posttraumatic growth is poorly understood and has a limited basis theoretically. They also reported that the measurement of the reliability and validity of posttraumatic growth was limited. Furthermore, posttraumatic growth is not necessary for successful recovery from PTSD.

Providing that the concept of posttraumatic growth is adequately researched and measured, it may prove to be a clinically useful factor when considering treatment planning for those with PTSD, although at present this is not supported by the literature.

1.1.7 The Effects of PTSD on Others

Although the majority of research on PTSD focuses on how the disorder affects the individual who has been directly traumatised, the research literature on how PTSD affects those who have been indirectly traumatised is growing. For many years it has been suspected that the effects of a person's PTSD can influence the emotional wellbeing of others (Brady *et al.*, 1999; McCann & Pearlman, 1990). However, the main focus of research has been on the experiences of therapists and other mental health workers (Lerias & Bryne, 2003; McCann & Pearlman, 1990; Sabin-Farrell & Turpin, 2003). In addition, more recent research has shown that people who have lived near the sites of major terrorist attacks and natural disasters, and the families of combat veterans have also been affected. What follows is a discussion of the main research findings for each of the groups noted above.

The main terms that have been used to describe the effects of patients' PTSD on mental health workers have been 'vicarious trauma' and 'secondary trauma'. However, these terms are often used interchangeably, are not clearly defined, and studies do not usually state which definition they are using when describing the results of their findings. The concept of vicarious trauma was first proposed by McCann and Pearlman (1990). Lurgis (2000) conceptualises vicarious trauma as the

impact felt by another person who is exposed to the explicit accounts of a person's PTSD. It has also been described as: '...the response of those persons who have witnessed, been subjected to explicit knowledge of or, had the responsibility to intervene in a seriously distressing or tragic event' (p.130; Lerias & Bryne, 2003). Secondary trauma has been defined as: '...a natural consequence of caring that happens between two people, one of whom has been initially traumatised and the other of whom is affected by the first's traumatic experiences' (Figley, 1995; p.9, cited in Collins & Long, 2003).

Lerias and Bryne (2003) reviewed the literature on vicarious trauma and suggested that the symptoms of vicarious traumatisation in therapists are similar to the symptoms of people with PTSD. For example, they reported that therapists can feel that they are 'helpless witnesses' to the patient's trauma, and that through empathising with the patient's distress the therapists can re-experience the traumatic context of the patient's disclosure. Lerias and Bryne also found that therapists can display a number of PTSD related avoidance behaviours, such as avoidance of feelings and avoidance of intimacy. People who experience vicarious traumatisation have also been shown to have an increased concern for their own safety. Lerias and Bryne reported that increased arousal was also common in people with vicarious traumatisation. They reported that the increased arousal could be expressed as anxiety, unexplained anger, sleeplessness and an increased sense of danger.

Brady *et al.* (1999) examined the effects of secondary traumatisation on mental health workers who worked with people who had been sexually abused. It was found that mental health workers with more experience of working with people who had been

sexually abused were more likely to experience increased levels of PTSD symptoms, as measured by the IES.

In a more recent study that examined the prevalence and correlates of secondary traumatisation in lay trauma counsellors, Ortlepp and Freidman (2002) used a mixed design of qualitative and quantitative methods to assess the experiences of 130 participants (lay trauma counsellors) who were employed in banks. It was found that although the participants in this study experienced a number of symptoms of secondary traumatic stress, their symptoms were not clinically significant. Ortlepp and Freidman suggested that as the lay counsellors were only working with trauma on a part-time basis, it was possible that the different work roles (i.e. working in the bank) may have buffered them from the effects of continued trauma exposure. This study also found that in contrast to previous research, the degree of injury inflicted in the bank robberies was not related to levels of secondary traumatisation in the lay counsellors. However, it was noted that there was a statistically significant inverse relationship between levels of social support and levels of secondary traumatisation ($r = -.4$), and this may have reduced the likelihood of the counsellors going on to develop PTSD related symptoms.

Sabin-Farrell and Turpin (2003) conducted a review of sixteen studies which focused on vicarious and secondary traumatisation in mental health workers. Their review covered both qualitative and quantitative studies. Sabin-Farrell and Turpin report that the two most commonly cited studies, which support the existence of vicarious traumatisation, are by Schauben and Fraser (1995) and Pearlman and Maclan (1995). Sabin-Farrell and Turpin reported a number of limitations in the above studies; for

example, both of the studies used correlational analyses and the correlations between vicarious trauma and other variables, such as therapist's beliefs, caseload size and number of years of experience of working with people with trauma were small (correlations ranging from $r=.16$ to $r=.27$). Furthermore, Sabin-Farrell and Turpin reported that, where standardised measures had been used, the measures had poor reliability or only a sample of items from the measures had been used. They concluded that the evidence to support vicarious traumatisation was meagre and inconsistent. It is also noted that the risk factors that increase a person's vulnerability to vicarious traumatisation are not clearly distinguished. However, they do suggest that, based on the findings of a small number of studies, it is possible that vicarious trauma exists, and that it might not be restricted to specialist trauma therapists. Sabin-Farrell and Turpin note that vicarious trauma could affect other professionals who work with trauma, and that the variety of clinical caseload may be an important factor to investigate; however, these are areas that require further research.

In addition to traumatic events having an effect on professionals who work closely with people who have been traumatised, a number of studies have looked at the effects that a traumatic event could have on people who have not been directly exposed to that event. For example, in a study of participants who were not directly exposed to bushfires in Australia, Bryne *et al.* (2006) found that of their 115 participants, almost half displayed symptoms of vicarious trauma (this was measured by an IES score of 9 or greater). They noted that the participants in their study who were vicariously traumatised were more likely to have had greater exposure to the bushfires through TV, radio and news reports, and they were more likely to have engaged in discussions regarding the bushfires. In addition, the vicarious trauma

group was more likely to have become distressed when learning about the bushfires and was more likely to have experienced greater levels of distress generally following the bushfires. They noted that the traumatised group was more likely to adopt avoidance as a general coping strategy. However, this study had a number of methodological limitations such as the use of a nonstandardised measure of vicarious trauma and the group reporting vicarious trauma comprised 46 in total. This may therefore limit the extent to which the results of this study can be generalised to other groups who have been vicariously traumatised. Furthermore, 18 comparisons were made between the two groups in this study and no correction procedures were used to reduce the effect of the multiple comparisons (type 1 errors).

In addition to natural disasters having an impact on those who indirectly witness them, the consequences of indirect exposure to acts of terrorism have also been studied. Blanchard *et al.* (2004) studied the effects of indirect exposure to the September 11th attacks in New York on 1369 college students from three different universities in New York and the surrounding area. They found high levels of acute stress disorder in the first few weeks following the terrorist attacks, with the highest levels being found in students who attended the university closest to the World Trade Centre. In addition, students whose permanent homes were closer to the World Trade Centre were more likely to report higher levels of stress than students who lived further away. Blanchard *et al.* noted that the levels of acute stress disorder in their New York sample were similar to those reported in a study of people who attended for treatment at hospital following motor vehicle accidents (e.g. Bryant *et al.*, 2000). Furthermore, meeting the criteria for acute stress disorder was a notable risk factor for the development of PTSD 6-10 weeks following the attacks. In terms of exposure to

the attack, Blanchard *et al.* measured the number of hours spent watching TV reports of the attacks and programmes which were devoted to the attacks, and found that this form of exposure was related to increased levels of acute stress disorder in two of the three university sites.

The research above provides an indication that being indirectly exposed to a traumatic event can have an impact on a person's well-being. It also appears that witnessing images of a trauma or recollections of a trauma from others whilst in therapy can have a significant effect. This is an interesting phenomenon, as it highlights that a person may not have to witness a traumatic event directly in order to experience negative consequences from that event.

PTSD can also have a direct effect on a person who has a close relationship with a person with PTSD. For example, a number of qualitative and quantitative studies outlined below have examined the experiences of the partners of combat veterans with PTSD and, although the literature on the relationships between vicarious/secondary traumatisation in the partners of combat veterans is equivocal, it does appear that there can be negative psychological consequences of having a close relationship with a person with PTSD.

Al-Turkait and Ohaeri (2008) assessed levels of PTSD in the wives of 176 Kuwaiti combat veterans who had served during the first Gulf War. They found that, although there was a significant association between the prevalence of PTSD and the degree of exposure to war of the husband, the relationship between husbands' and wives' levels of PTSD was not significant. Al-Turkait and Ohaeri noted that, although the wives

seemed to have been affected by the degree of trauma exposure of their husbands, they had not been affected by the specific nature of PTSD in their husbands. They suggested that for the women in their study, levels of PTSD were related to their experience of being in Kuwait during the invasion, rather than the effects of being vicariously traumatised by the experiences of their husbands.

Studies have shown that living with someone with a severe mental illness can result in increased levels of psychological distress among family members (e.g. Baronet, 1999). This finding has been observed in family members of people with schizophrenia (Oldridge & Hughes, 1992), bipolar depression (Perlick *et al.*, 2001) and obsessive compulsive disorder (Renshaw *et al.*, 2000).

Beck *et al.* (2009) assessed 109 survivors of serious motor vehicle accidents. Participants completed measures of PTSD and rated their perceived interpersonal functioning within the domains of close friendships, social life, romantic relationships and family relationships. It was found that increased hyperarousal symptoms were associated with greater strain in relationships with best friends. In addition, increased emotional numbing symptoms were associated with a reduction in perceived social support from friends and romantic partners. However, the data in this study were derived from the participant's perception of how they affected their significant others, rather than from accounts from the significant others themselves.

Lyons (2001) conducted qualitative interviews with 10 wives/female partners of Vietnam veterans. The purpose of her study was to describe the experiences of women who lived with combat veterans who have PTSD. Lyons found that the partners of veterans would often speak about the veteran's feelings, needs and

experiences as if they were their own. Furthermore, the participants developed the symptoms of secondary traumatisation (Figley, 1995), such as anxiety, hypervigilance, lack of trust and somatic complaints. Lyons noted that for the partners of veterans with PTSD: '[Their]...experience is a gradual process of becoming enmeshed in the veteran's pathology, with all energies being directed at minimising the effect on the self and the family' (p. 69). Lyons concluded that all of the participants in her study experienced some degree of secondary stress as a result of looking after their partners. She also found that many of her participants reported feeling depressed and suggested that further research should employ a quantitative methodology to investigate the relationships between the severity of PTSD in veterans and levels of depression in their wives/partners.

Dekel *et al.* (2005) provided a more recent qualitative study which examined the experiences of nine wives of combat veterans. They found that the wives lived in fear of possible suicide attempts by their partners, and that this, in addition to the fear of disaster from the illness, overshadowed their lives. Dekel *et al.* noted that: 'The women's total immersion in the husband's mental state drew them into his tortured emotional world' (p. 28). As with the Lyons (2001) study, participants in the Dekel *et al.* study reported symptoms that were consistent with secondary traumatisation. Furthermore, the participants who were struggling to cope reported feeling as if they were living with a child or someone who was ill and in need of considerable care. However, where the marital relationship had been strong prior to the trauma, the caregiving spouse experienced greater levels of marital satisfaction.

In addition to the qualitative studies reported above, there are a number of quantitative studies that have examined the relationships between veteran PTSD and its effects on others. Westerink and Giarratano (1999) assessed the effects of PTSD on the families of Vietnam veterans from Australia. This study assessed 31 female partners and 15 adult controls. In addition, the children (all over age 15 years) of veterans were also assessed (24 children and 14 controls). This study used reliable and valid measures of emotion (General Health Questionnaire [GHQ 28]; Goldberg & Hillier, 1979) and PTSD (Clinician Administered PTSD Scale [CAPS]; Blake *et al.*, 1995). On the GHQ 28 partners showed significantly higher (more severe) scores than controls on all four subscales of the GHQ 28. These included somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. Furthermore, the partners in this study were four times more likely to show significant distress when compared with the control group. Westerink and Giarratano also reported that partners had significantly lower self-esteem than controls and that one third of the partners who reported previous trauma said that it was a result of the veteran's previous violence towards them. However, the results for the children showed that they did not experience the same level of distress as their mothers. For example, none of the GHQ 28 comparisons between the children of veterans and controls were statistically significant; however, 36.4 per cent of the veterans' children scored above the cut off for levels of significant distress, whereas only 14.3 per cent of controls scored above the cut off level. These are interesting findings, although there are a number of methodological limitations such as a small *N*, failing to provide information on the length of time since the trauma, and reporting that a random sample was used, but not reporting the method of randomisation. The study may have benefited from conducting a follow-up reassessment, as this could have provided greater validity than a cross sectional

design. There were also a number of issues relating to the appropriateness of the control group, which consisted of university staff who are likely to possess higher socioeconomic status. A more valid comparison group would be partners of combat veterans who had not experienced PTSD and were matched for age and socioeconomic status. This study may only be generalisable to the female partners of Vietnam combat veterans.

Dirkzwager *et al.* (2005) investigated the relationships between PTSD and the corresponding psychological distress experienced by the partners and parents of 1040 male Dutch peacekeeping soldiers. The psychological impact on significant others was assessed using the sleeping and somatic problems subscales of the Symptom Checklist-90 Revised (SCL-90-R; Derogatis, 1983). Significant others also completed a self-report measure of PTSD (e.g. Self Rating Inventory of PTSD (SRIP) (Hovens *et al.*, 1994) and a self-report measure of social support. Differences on these measures were examined by comparing the significant others of veterans with no PTSD symptoms, with the significant others of veterans with 1-3 PTSD symptoms. Dirkzwager *et al.* found that the partners of veterans with PTSD symptoms were significantly more likely than the controls to have sleep difficulties, somatic symptoms and PTSD symptoms. They were also more likely to have higher levels of negative social support (although no examples were given of what would constitute negative social support). However, similar results were not found for parents as a group, but it was shown that mothers were more likely than fathers to experience sleep problems, somatic complaints and PTSD symptoms. The evidence provided by this study might suggest that females are more likely than males to be affected by a significant other with PTSD. However, this hypothesis would have to be tested

directly and was not included in this study. The study has a number of limitations. For example, there was no randomisation of participants and female partners were not compared with mothers on any measures. Comparing partners and parents could have provided valuable information on which group of significant others (partners or mothers) were most likely to experience psychological distress. Furthermore, as increased levels of anxiety and depression are frequently found in the significant others of veterans with PTSD, they may have been mediating variables. The inclusion of the SCL-90-R anxiety and depression scales might have allowed this to be accounted for. The study focused on a specific subpopulation of partners and parents of peacekeeping combat veterans. It is therefore likely that results are not generalisable beyond the partners and parents of combat veterans.

Beckham *et al.* (1996) investigated the relationships between veterans PTSD and its effects on their partners. PTSD was assessed using a scale designed for combat veterans (Mississippi Scale for Combat-Related PTSD; Keane *et al.*, 1988). They assessed 58 Partners using the Burden Inventory (BI; Zarit *et al.*, 1980) (a self-report measure that assesses levels of perceived burden in the caregivers of people with physical or mental illnesses), the SCL-90, the Beck Depression Inventory (BDI; Beck, Ward & Mendleson, 1961) and the Spielberger State and Trait Anxiety Inventory (STAI; Spielberger, 1983). It was found that 36 per cent of partners reported moderate or greater scores on the BDI. In addition, the mean scores for state and trait anxiety were also within the moderate range. Beckham *et al.* found that there was a significant relationship between veteran levels of PTSD and the levels of burden in the partners ($r=.52$), with higher levels of veteran PTSD being related to higher levels of partner burden. Furthermore, veteran PTSD was also related to increased levels of partner

psychological distress, dysphoria and state and trait anxiety. This study has a number of methodological limitations. For example, the number of participants in the study was small. In addition, the authors stated that the veterans had chronic PTSD without stating the chronicity of the PTSD. Chronicity of PTSD was not included as a variable, and this may have had a direct impact on the partner's perception of burden. They suggested that burden increases with time and is associated with severity of PTSD; however, no information is provided on the length of time since the trauma. Although information on levels of significant other burden were provided following an eight month follow-up period, this is a short period of follow-up and twelve to eighteen months would have provided a more clinically meaningful period in which to determine the degree of sustained change. There was no control group.

Evans *et al.* (2003) investigated the effects of PTSD on the family functioning of 270 Vietnam veterans and their families. Veterans completed the military version of the PTSD checklist (PCL-M; Weathers *et al.*, 1993), the GHQ-28 and the McMaster Family Assessment Device (FAD; Epstein, Baldwin & Bishop, 1983). Their partners also completed the FAD. The FAD is an assessment of family functioning which measures issues such as problem solving, communication, affective responsiveness and behavioural control. Evans *et al.* provide an addition to the research literature by examining the subcategories of PTSD symptoms (intrusion, avoidance and arousal). The results of path analysis suggested that there was a significant relationship between PTSD avoidance and family functioning for veterans. In addition, PTSD arousal was related to levels of anger, but not family functioning. They suggested that this means that PTSD arousal symptoms were mediated by anger. The impact of depression in veterans was also assessed and it was found that depression was related

to poor family functioning. This study also found that the FAD scores of the partners were correlated with veteran PTSD avoidance and intrusion, and partner FAD scores were significantly related to increased levels of veteran anger and alcohol abuse. Nevertheless, it should be kept in mind that all of the correlations were small ranging from .12 to .16. Evans *et al.* suggest that avoidance and arousal symptoms have interpersonal implications for veterans and their partners. However, they also report that the partner's accounts of poor family functioning might be related to anger rather than PTSD. This study provides a useful contribution to the knowledge base on how PTSD affects veterans and their families; however, there are a number of methodological limitations which should be considered when interpreting the results. For example, the reliability (test-retest) of the FAD is moderate .66 to .76, the chronicity of PTSD was not reported or used as a variable, and the study was conducted with veterans, thereby limiting the extent to which the results can be generalised to other populations.

Manguno-Mire *et al.* (2007) investigated the relationships between levels of PTSD in combat veterans and the corresponding effects of burden and psychological distress in their partners. They assessed 89 female partners of combat veterans with PTSD. Veteran PTSD status was obtained from a diagnosis in their medical notes and the PCL-M. Partners completed the Burden Inventory and the Brief Symptom Inventory 18 (BSI-18; Derogatis, 2001), which measures anxiety, depression and somatisation. The total BSI scores for the partners revealed that they were experiencing a high degree of psychological distress with the mean total BSI score ranking in the 90th percentile. Furthermore, the scores for the individual subscales of BSI were also all in the 90th percentile. They found that 15 per cent of partners reported recent suicidal

ideation and that over 60 per cent of the partners felt threatened by their relative with PTSD. A multiple regression analysis showed that there were a number of factors which were predictive of the partner's perception of burden. These were severity of PTSD in the veteran, partner treatment engagement, perceived barriers to treatment, partner self-efficacy and perceived threat. They also noted that partners who had the highest distress scores were more likely to have received treatment from the mental health services. In addition, significant correlations were found between veteran PTSD and partner distress (.28), veteran PTSD and partner burden (.38) and partner burden and partner distress (.67). Interestingly, it was observed that greater involvement of partners with their veteran husbands was associated with decreased psychological distress in partners. Manguno-Mire *et al.* suggest that partners who are more involved with their husbands may benefit from the buffering effect of social support and the reduction in stress that social support provides (e.g. Pretorius, 1997). They hypothesised that, as avoidance is a common problem in PTSD, sharing pleasurable activities with a partner may lead to greater cohesion in the relationship. However, the associations between PTSD avoidance symptoms and partner social support were not directly tested in this study.

A number of methodological limitations were present in the study. For example, the length of time since the trauma was not reported or studied. This was an important omission, as veterans had potentially experienced PTSD for more than 30 years, which could therefore result in more entrenched PTSD, which could possibly cause higher levels of burden in significant others, when compared with the significant others of those who have been traumatised more recently. In addition, no follow-up measures were completed. The study has focused on the female partners of combat

veterans; therefore it is difficult to generalise the results to the caregivers of non-combat veterans with PTSD or to male caregivers of people with PTSD.

Calhoun *et al.* (2002) assessed the relationships between veterans' PTSD, significant other burden and significant other psychological distress in a sample of 51 partners of Vietnam War veterans. A group of 20 partners of veterans who did not have PTSD were also assessed. Veterans were assessed using the Mississippi Scale for Combat-Related PTSD (Keane *et al.*, 1988), and female partners completed the Burden Inventory (Zarit *et al.*, 1980), and the SCL-90-R (which measures somatisation, obsessive compulsive symptoms, interpersonal sensitivity, depression, anxiety, paranoid ideation and psychoticism). Partner social support was also assessed using a single item unstandardised measure. They reported that when compared with partners of veterans without PTSD, partners of veterans with PTSD experienced greater burden and psychological distress. The partners of veterans with PTSD experienced greater levels of depression, anxiety, hostility and obsessive-compulsive symptoms. However, the relationships between the aforementioned conditions and levels of burden and PTSD were not reported. There were significant relationships between partner/significant other burden and veteran PTSD ($r=.38$), and partner burden and reported violence ($r=.55$). Calhoun *et al.* noted that the results of a multiple regression analysis suggested that, after significant other burden and interpersonal violence had been adjusted for, veteran PTSD was not uniquely related to partner psychological adjustment. In addition, they found that the availability of social support did not moderate the relationship between PTSD severity and significant other burden. This study supports a number of the findings of previous research; however, there are a number of methodological limitations which should be discussed. For example, they

conclude that social support received by partners was not related to levels of partner burden or levels of veteran PTSD, yet social support was not measured with a standardised measure, rather it was assessed using a single item question. Furthermore, the participants were not randomly selected and no indication was given about the duration since the trauma. This is important, as the study focuses on 'chronic' PTSD and the mean age of the participants is 50 years. Moreover, the authors did not define what they meant by 'chronic' PTSD. Further limitations include a large difference in numbers between the PTSD and control groups, 51 and 20 respectively. The study was cross-sectional and no follow-up was conducted.

Taken together the results from the studies above suggest that there are significant relationships between increased levels of patient/veteran PTSD and increased levels of partner/significant other anxiety, depression, burden and anger. There is a lack of research which examines the relationships between PTSD and the emotional effects of living with or caring for a person with PTSD. Increased levels of PTSD have been linked to increased levels of anxiety (e.g. Beckham *et al.*, 1996; Calhoun *et al.*, 2002; Lyons, 2001) and depression (e.g. Beckham *et al.*, 1996; Calhoun *et al.*, 2002; Manguno-Mire *et al.*, 2007; Westerink & Giarratano, 1999) in partners/carers in a number of studies. In addition to the impact of PTSD on the emotional wellbeing of significant others, the role of perceived burden has also been linked to emotional distress in the significant others of people with PTSD (e.g. Calhoun, *et al.*, 2002; Manguno-Mire *et al.*, 2007).

1.2 Burden

1.2.1 Definition of Burden

In her review of the literature on significant other burden, Baronet (1999) described two types of burden: objective burden and subjective burden. *Objective burden* relates to the observable effects that the patient's illness has on the significant other's household and the demands that are placed on other members of the family. This can include changes in the behaviour and personality of the person being cared for, financial strain, providing transportation and changes in previously enjoyed social activities of the significant other. Objective burden is more likely to be the result of activities related to caring for the patient, rather than as a result of the behaviour of the patient. *Subjective burden* relates to the significant other's personal views and beliefs about their situation and the extent to which they feel that they are bearing the load of the person for whom they are caring. This aspect of burden relates to the extent to which the significant other feels that they are stressed or under strain. Subjective burden is more likely to be related to the behaviour of the patient, rather than the demands of caregiving.

1.2.2 The Relation of Burden to Psychiatric Illness

According to Ohaeri (2003), the concept of burden for family caregivers is a highly topical issue as it represents the effects of an 'invisible healthcare system'. The concept of burden has received considerable research interest over the past three decades and a number of reviews of the literature have been conducted. Initially the research on burden was focused on the experiences of significant others who were looking after older adults with dementia (Schulz *et al.*, 1995). However, research has

also considered the impact of burden on the significant others of people with severe mental illnesses such as schizophrenia (Baronet, 1999). The impact of burden from caring for people with heart disease (Magliano *et al.*, 2005), cancer (Groves *et al.*, 2006), and diabetes (Magliano *et al.*, 2005) has also been examined.

Baronet (1999) reviewed the findings of fifteen studies which examined factors related to significant other burden. Significant correlations were found between levels of burden and the significant other's age. Significant others who lived with their ill relative were also more likely to experience higher levels of burden than those who did not live with their ill relative. However, no relationships were found between increased levels of burden and significant other's education, family income or the ill relative's gender. Biegel *et al.* (1994) assessed 103 significant others of people with chronic mental illness and found that ill relatives' behaviours (e.g. sleeping problems, not taking medication, poor money management and suspiciousness) and the absence of family support were associated with increased subjective burden. Furthermore, in a study of 134 carers of people with severe mental illness, it was found that higher levels of subjective burden were related to younger age, poorer psychological adjustment, ethnicity (being white), and number of years that the ill relative had experienced illness (Cook *et al.*, 1994). In a further study of the relatives of adults with severe mental illness, Greenberg *et al.* (1997) assessed 164 significant others. They found that caring for a relative with schizophrenia, younger caregiver age, psychiatric symptoms and an interaction between attribution of control and symptoms accounted for 32 per cent of the variance in the stigma aspect of subjective burden. When measuring the burden related to the stigma of having a significant other, they used a measure of stigma which includes items which assess the extent to which

family members avoid disclosing their significant other's mental illness due to worries regarding what others might think (non-standardised measure). Higher levels of perceived stigma were related to higher levels of perceived burden in significant others.

Baronet (1999) noted that mixed results had been found regarding the relationship between social support and significant other burden. In the six studies reviewed, social support was not related to objective burden, although some evidence was found to support the relationship between social support and overall burden and subjective burden. For example, Song *et al.* (1997) studied the relationships between levels of burden, significant other depression and levels of social support in 103 significant others. Song *et al.* found that the largest predictor of burden was poor social support. Furthermore, they also reported that that high levels of burden were related to increased levels of depression. In addition, a four year longitudinal study by Canuscio *et al.* (2002) found that significant others who provided more than 36 hours of care per week were six times more likely to experience depressive or anxious symptoms when compared with non caregivers.

Recently, Phillips *et al.* (2009) found that in a non diagnosis specific study of 393 caregivers in Scotland, levels of burden were significantly correlated with levels of depression and poorer sleep quality. Furthermore, levels of burden were also significantly associated with levels of anxiety in caregivers, and levels of burden positively predicted levels of anxiety following a five year period.

1.2.3 Burden Related to Post Traumatic Stress Disorder

A small number of studies have examined the effects of caring for people with PTSD. One of the earliest studies to investigate this issue was conducted by Beckham *et al.* (1996). Beckham *et al.* assessed 58 partners of combat veterans and found that there were significant relationships between veterans' levels of PTSD and levels of burden in their partners, with higher levels of PTSD in veterans being related to higher levels of partner burden. In addition, Beckham *et al.* reported a significant positive relationship between levels of burden and levels of caregiver anxiety and depression.

Ben Arzi *et al.* (2000) compared the effects of burden and psychological distress in the wives of Israeli combat veterans with PTSD, wives of combat veterans with post-concussion injuries and a control group. Burden was measured using self-report measures of perceived burden. They found that levels of burden were significantly higher in the PTSD and post-concussion groups when compared with controls. Furthermore, levels of psychological distress were also significantly higher in the PTSD and post-concussion groups when compared with controls. Within the sample, all burden subscales were significantly correlated with levels of psychological distress ($r=0.62 - r=0.81$). However, it should be noted that the N for each group was small ($N=20$) and this is likely to have affected the power of the study. In addition, the control group was biased in terms of levels of education, earnings and they were not the partners of veterans. These factors are likely to have had an effect on the validity of the comparisons.

Calhoun *et al.* (2002) reported significant relationships with significant other burden and PTSD, and partner burden with reported violence. In this study the largest

correlation with caregiver burden was levels of violence from the partner ($r=.55$). Although significant others completed measures of anxiety, depression and other psychological problems, the relationships between these scores and levels of burden were not reported. Further examination of the relationships between burden and significant other psychological distress would have provided valuable information in the understanding of how burden is related to the psychological wellbeing of significant others.

In another study of the effects of caregiving on those who live with people with PTSD, Manguno-Mire *et al.* (2007) assessed the partners of veterans with PTSD. They found significant correlations between high levels of veteran PTSD and high levels of partner burden, and partner burden and partner psychological distress. In addition, significant relationships were reported between levels of partner burden and veteran-partner involvement (more involvement = less burden), perceived threat, caregiver self-efficacy, perceived barriers to treatment and perceived benefits of treatment. The authors used a composite score for psychological distress and the specific relationships between levels of burden, anxiety and depression were not reported. However, Manguno-Mire *et al.* have suggested that reductions in levels of partner burden may have a positive reciprocal effect on improving veteran PTSD symptomatology, although this requires empirical investigation.

The results above highlight the relationship between caring for a person with PTSD and subsequent significant other burden. However, it has been argued that further investigation is required into the effects of burden on the significant others of less studied populations, such as the significant others of people with PTSD (e.g. Kalra, *et*

al., 2008; Ohaeri, 2003). This argument is particularly valid at present, as all of the studies discussed so far have focused on the significant others of combat veterans with PTSD. At present, there is a paucity of research which examines the relationship between levels of burden and PTSD in non-combat veteran populations. This will be the area of examination in the present research study.

Although the present study is assessing levels of burden and levels of depression separately, it should be noted that there is a potential conceptual confound between these two factors. The overlap between depression and burden has not been discussed in the existing literature; however, there is a potential confound between the manner in which a person experiences burden and depression. For example, in her description of burden, Baronet (1999) suggested that people who experienced burden were less likely to enjoy social activities with their significant others. However, a lack of interest in social activities is also common in people who are depressed. In addition, burden involves feeling under strain and a poor perception of one's ability to cope. These are also difficulties which are commonly found in people with depression and anxiety. Furthermore, feelings of helplessness are often reported in both depression and burden and it is therefore likely that this is a factor which straddles both difficulties. Therefore, the lack of conceptual independence between depression and burden should be considered when interpreting correlations between these measures.

1.3 Anxiety

1.3.1 Definition of Anxiety

The present study is interested in levels of anxiety, as measured by self-report standardised measures, rather than specific diagnoses of anxiety disorders. A number of studies have used the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) to assess levels of anxiety. The HADS assesses common anxiety related experiences, such as feeling tense and wound up, feeling frightened, having worrying thoughts, being unable to sit and feel relaxed, restlessness, and sudden feelings of panic. It has been used to detect anxiety in a wide variety of populations, such as primary care patients with anxiety (Bjelland *et al.*, 2002; Runkewitz *et al.*, 2006), cancer patients (Myskaidou *et al.*, 2005) and panic disorder patients (Lowe *et al.*, 2003).

Anxiety symptoms have also been assessed using a variety of other self-report measures in people with PTSD (e.g. Beckham *et al.*, 1996; Westerink & Giarratano, 1999) and their significant others (e.g. Al-Turkait & Ohaeri, 2008; Beckham *et al.*, 1996; Manguno-Mire *et al.*, 2007).

1.4 Depression

1.4.1 Definition of Depression

This study is interested in levels of depression, as measured by self-report standardised measures, rather than specific diagnoses of depressive disorders. A number of studies have used the HADS in the assessment of depression. The HADS

assesses common depressive experiences, such as a lack of enjoyment of activities, feeling sad, feeling slowed down, loss of interest in appearance and pessimism for the future.

The HADS has identified depression in a number of populations, such as primary care patients with depression (Bjelland *et al.*, 2002; Runkewitz *et al.*, 2006), cancer patients (Myskacidou *et al.*, 2005) and patients with PTSD (Evans *et al.*, 2003). Alternative self-report measures have also been used to measure depression in people with PTSD (e.g. Beckham *et al.*, 1996; Westerink & Giarratano, 1999) and their significant others (e.g. Al-Turkait & Ohaeri, 2008; Beckham *et al.*, 1996; Manguno-Mire *et al.*, 2007).

1.5 Social Support

1.5.1 Definition of Social Support

Since the 1970s there has been increasing interest in the role of social support as a coping resource (Zimet *et al.*, 1988), and it has been shown to be a protective factor against stress and depression (Vilhjalmsson, 1993). A number of authors have attempted to define social support. For example, Shumaker and Brown (1984) suggested that social support was ‘...an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the wellbeing of the recipient’ (p.13). Social support has also been defined as ‘...perceived or actual instrumental and or expressive provisions supplied by the community, social networks, and confiding partners’ (p.18; Lin, 1986).

1.5.2 The Role of Social Support

Social support has also been shown to be an important protective factor for patients with PTSD (Brewin *et al.*, 2000), although in a study which examined the role of social support in the significant others of people with PTSD, partner/carer social support was not related to patient PTSD or levels of burden (Calhoun *et al.*, 2002). Due to the limitations in the way in which social support was measured and the small number of participants in that study, the relationships between carer/partner social support, perceived burden and emotional distress warrant further investigation.

All of the studies described above have been based on the experiences of combat veterans and their families. It is therefore necessary that studies are conducted on samples which are more representative of the population who present for treatment of PTSD and their families, as it is likely that the life experiences of veterans will be different from those of patients who have been involved in other traumatic events, such as motor vehicle accidents; therefore, the differences in traumatic events could then have an impact on the ways in which patients interact with their significant others. It is also noteworthy that veterans face different challenges in their lives, such as the transition from military to civilian life. As anxiety, depression and levels of burden in partners/ carers have all been shown to be related to levels of PTSD in patients/veterans, these factors with the addition of social support for partners/carers will be described in greater detail.

1.5.3 Social Support and PTSD

The relationship between poor social support and increased severity of PTSD has been well documented in the research literature (e.g. Brewin *et al.*, 2000; Ozer *et al.*,

2003). In addition, a recent study examined the relationships between how combat veterans perceived social support from friends, non veteran friends, their spouse and relatives. It was found that higher levels of PTSD were correlated with the perception of less social support. Furthermore, the source of social support was an important factor, as veterans viewed their veteran friends as more supportive than their spouse (Laffaye *et al.*, 2008). However, as mentioned above, few studies have examined the effects of social support on the emotional wellbeing of people (e.g. caregivers/partners) who have a close relationship with people with PTSD. One study which examined the relationships between veteran PTSD, significant other support and significant other burden found that the levels of social support that were received by the significant other were not related to either their partner's levels of PTSD or their own perception of burden (e.g. Calhoun *et al.*, 2002).

1.5.4 Social Support and Other Psychological Problems

In contrast to the relationships between social support, burden and psychological functioning in significant others of people with PTSD, a study which examined the effects of social support in the significant others of people with chronic mental illness (Song *et al.*, 1997) found that the largest predictor of significant other burden was poor social support. In addition, poor social support was also related to increased levels of depression in this sample.

The concept and provision of social support is important, as a study by Dean and Lin (1977) showed that social support can act as a buffer between stressful events and psychological distress. In addition, social support has been shown to be a protective factor for depression in a one-year prospective study (Monroe *et al.*, 1986). Lyons *et*

al. (1988) examined the effects of perceived social support in three different samples. These were patients with a chronic psychiatric illness (undefined), people with diabetes and a student sample. Lyons *et al.* found that perceptions of social support were significantly higher in the student and diabetic groups than in the psychiatric patients group. In the psychiatric group, levels of perceived social support were significantly negatively correlated with levels of depression.

1.6 Positive Aspects of Caregiving

The role of positive factors in caregiving has been relatively neglected in caregiving research (Hilgeman *et al.*, 2007). Bulger *et al.* (1993) have suggested that although it can be easy for people to recognise that looking after people with mental illnesses can cause burden, it is not usually as obvious that caregiving can also be rewarding. As with the positive aspects of PTSD discussed in section 1.1.6, there can also be a number of positive factors related to caring for people with mental health problems, including caring for a person with PTSD. Indeed, it has been reported that most families can identify one or more strengths from dealing with a family member who experiences mental illness (Chen & Greenberg, 2004; Greenberg *et al.*, 2000). When considering the positive aspects of caregiving three main factors have been suggested: satisfaction from the interpersonal dynamic between carer and cared for; satisfaction from the intrapersonal or intrapsychic orientation of the carer and a desire to promote positive outcomes and avoid negative outcomes for the person who is being cared for (Nolan *et al.*, 1996).

In a study of positive aspects of caregiving, Cohen *et al.* (2002) examined the experiences of 239 carers of people with dementia. They found that over seventy per

cent of the caregivers felt that they were happy about providing care or had positive feelings whilst providing care. They found that the common positive aspects were companionship and fulfilment. Duty and obligation were also reported, as were enjoyment. They found that caregivers' positive experiences were negatively correlated with caregiver depression, burden and self-assessed health. They suggest that levels of satisfaction with caregiving could be used as a risk factor for identifying carers who might be susceptible to depression and other health related problems.

Veltman *et al.* (2002) adopted a qualitative approach to investigate the positive and negative experiences of the caregivers of people with schizophrenia, schizoaffective disorder, chronic depression and bipolar disorder. They found that eight of the twenty caregivers interviewed revealed that that had been diagnosed with depression following the onset of their relative's mental illness. They found two main positive themes, which were 'love and care for an ill relative' and 'life lessons learned'. The first theme involved satisfaction with having been able to help a relative, love and hope and pride. The second theme highlighted the caregiver's experiences which taught them to be more compassionate towards their relative and to others. The experiences of one caregiver of a person with bipolar disorder are useful in highlighting the complex nature of the positive and negative aspects of caregiving. She said 'Caregiving is sometimes very joyful, sometimes very painful, sometimes sad, lonely...a lot of feelings mixed up'

(p. 113).

Chen and Greenberg (2004) investigated the predictors of caregiving gains in 493 caregivers of relatives with schizophrenia. They found that higher levels of caregiving

gains were predicted by being female, having fewer years of schooling, being a parent and living with a relative with schizophrenia. In addition, caregiving gains were predicted by receiving information about mental illness and its treatment and the participants feeling that they were treated as collaborators in the treatment process. Informal social support gained through participation in a support group and contributions from the relative with mental illness were also shown to be predictive of caregiver gains. However, the level of the relative's psychiatric symptoms was unrelated to levels of caregiver gains.

The longitudinal effects of caregiving gains in a sample of 124 caregivers of people with Alzheimer's were examined over a twelve month period (Hilgeman *et al.*, 2007). It was found that decreases in levels of daily care burden and lower levels of depression were predictive of increased perception of caregiving gains at baseline; however, these relationships were not significant following a twelve month period. Positive gains were stable over time and it was suggested that a person's outlook on life and their appraisal of their role as a caregiver may account for this. Hilgeman *et al.* (2007) suggest that interventions aimed at increasing positive reappraisal of the caregiving role may help to facilitate continued coping in caregivers. In addition, interventions targeting caregivers with low levels of positive gains may reduce health care costs and be cost effective.

The majority of the above studies have focused on the positive aspects of caring for relatives with Alzheimer's disease or mental illness. Unfortunately, there are currently no studies examining the positive effects of caring for, or having a close relationship with a person with PTSD.

1.7 Study Rationale

The present study is necessary for a number of reasons. For example, there is limited evidence from non-combat based samples on the relationships between PTSD and emotional problems in the significant others of people with PTSD. This is important, as it should not be assumed that the way PTSD affects a veteran's significant others will be the same as the way in which PTSD affects the significant others of people with non-combat related PTSD. For example, combat veterans are likely to have experienced type II traumas, which have been present for many years. This might cause a change in their personality and the way that they respond to others, whereas the same personality and behavioural changes might not be present in patients who have experienced type I non combat related trauma (see Herman, 1992).

Furthermore, the studies which investigated the relationships between PTSD in patients and burden, anxiety, depression and perceived social support in significant others were based on the veterans of Australian, Dutch and American combat veterans and their wives who were treated through veteran treatment programmes. However, the current study is focused on investigating these relationships with trauma patients from the UK with a wide variety of traumatic experiences, and does not exclusively focus on the treatment of combat veterans.

The present study will focus on the role of social support in significant others, rather than the role of social support in people with PTSD. Only one study assessed the relationship between levels of social support in significant others and significant other burden (Calhoun *et al.*, 2002). As this study did not use standardised measures of social support, the validity of the findings regarding significant others' perceptions of

social support are therefore limited. The present study will use a standardised measure of social support to assess the relationships between social support and burden in the significant others of people with PTSD.

Furthermore, the current study is interested in the experiences of a wider range of significant others than have been reported in the studies described above. For example, in addition to studying the levels of burden, anxiety, depression and social support in the partners of those with PTSD, the present study will also include the experiences of other close family members and close friends who provide social support to those with PTSD. This inclusion broadens the parameters of investigation and may provide useful evidence regarding the extent to which PTSD impacts on a person's social support network.

Based on anecdotal reports from therapists working in NHS settings, it is anticipated that there might be an association between levels of PTSD in patients and a corresponding impact on their significant others, which would be in line with the combat-related literature. Furthermore, as the present study will use similar symptom-based self-report measures to those used with combat populations, it is hypothesised that similar results might be found to those reported in the existing literature.

1.8 Aims and Hypotheses

The proposed study aims to investigate the following research hypotheses:

Primary Hypotheses

1. High scores for patients on the Impact of Event Scale-Revised (IES-R) will be associated with high levels of burden in significant others, as measured on the Burden Inventory (BI).
2. High scores for patients on the IES-R will be associated with greater levels of anxiety in significant others, as measured by the Hospital Anxiety and Depression Scale (HADS).
3. High scores for patients on the IES-R will be associated with greater levels of depression in significant others, as measured by the HADS.
4. High scores for patients on the IES-R will be associated with greater levels of psychological distress in significant others, as measured by the total score on the HADS.

Secondary Hypotheses

5. Increased BI scores will be associated with increased significant other anxiety, as measured by the HADS.
6. Increased BI scores will be associated with increased significant other depression, as measured by the HADS.
7. Increased BI scores will be associated with increased significant other psychological distress, as measured by the HADS total score.
8. Levels of perceived social support by significant others, as measured by the Multidimensional Scale of Social Support (MSPSS) will be related to significant other burden, as measured by the BI.

9. Levels of perceived social support by significant others, as measured by the MSPSS will be related to anxiety, as measured by the HADS.
10. Levels of perceived social support by significant others, as measured by the MSPSS will be related to depression, as measured by the HADS.

2.0 Method

2.1 Ethical Issues

Ethical approval was granted by NHS Lothian Research Ethics Committee (see appendix 3). Patients may not have wanted their significant other to know about their treatment. Therefore, patients were free to decide if they wished to inform their significant other about the study. If they did not want anyone to know about their treatment, they could simply decline. Patients did not have to decide to participate at the point of assessment, as they had seven days to decide. If they participated, questionnaires were returned in a stamped addressed envelope. Patients were assured that if they declined, it would not affect their treatment in any way.

Although burden was studied, the term 'burden' was not used on any information sheets or the questionnaires. The word was omitted as it may have caused distress to the patients if they felt that they were burdening their significant others.

2.2 Participants

2.2.1 Recruitment

Two groups of participants were recruited in two stages. The first group were patients and the second group were the nominated significant others of the patients.

Patients

The first stage involved the recruitment of NHS patients who had been referred for assessment and treatment of post traumatic stress at an NHS trauma clinic and an area-wide clinical psychology department in Scotland. Patients were referred by

General Practitioners and Psychiatrists. At the end of the first assessment or treatment session, therapists introduced the study to patients and provided patient information sheets (see appendix 4) and a copy of the demographics questionnaire (see appendix 5). Patients were free to ask questions about the study at any point.

Significant Others

Part of the demographics questionnaire requested the nomination of a significant other. A pre-study participation information sheet (see appendix 6) was also provided to the patient to give to their significant other. A significant other in the present study is defined as a person who has a close personal relationship with a patient with PTSD. This can include anyone from a close friend to a partner or family member. When a patient returned their questionnaire, this provided the name and address of a significant other who might be interested in participating. Significant others were then contacted by post by the researcher and were invited in a cover letter (see appendix 7) to take part. If they agreed they returned the questionnaires using the stamped addressed envelope. The significant other could be a family member (such as a partner, parent, sibling, grandparent or cousin) or close friend.

2.3 Design

In order to ensure the comparability with previous studies a questionnaire based methodology was used. In addition, as there were no studies which assessed patients from UK based clinics, a naturalistic approach was chosen to provide an indication of the nature and severity of PTSD experienced by patients and the corresponding effect on their significant others. Furthermore, based on the results of previous studies and

the knowledge that about 120 people are assessed each year in the trauma clinic, it was predicted that there would be sufficient numbers to conduct a quantitative study.

The present study is a naturalistic study, the only exclusion criterion for the significant others being the presence of a diagnosis of PTSD. If the significant other had PTSD (this information was obtained from the significant other's demographics questionnaire, see appendix 8) they were excluded, in order to avoid confounding the results. The exclusion criterion was implemented, as otherwise it would be difficult to determine if their psychological distress and burden were the result of their own PTSD or from supporting the patient.

The study was cross-sectional in nature and adopted a mixed correlational design. To reduce the pressure on significant others to participate in the study, a postal survey was used instead of face-to-face interviews. Thus, the significant other could opt out by not completing and returning the measures. It was decided that postal surveys were preferable to face-to-face interviews, even though the response rate for data collection would be lower (e.g. Hox & De Leeuw, 1994). Telephone interviews were also considered, although this method may have made significant others feel obliged to participate. Furthermore, telephone interviews rely on the significant other owning a telephone.

2.3.1 Postal Surveys

A meta-analysis found that response rates for published studies varied depending on the method of data collection (Hox & De Leeuw, 1994). Hox and De Leeuw (1994) reviewed 45 studies and found that the response rate for face-to-face interviews was

70.3 per cent, telephone surveys was 67.2 per cent and postal surveys was 61.3 per cent. Due to ease of implementation and relatively low costs, postal surveys are used most frequently. The literature suggests that the better the survey the higher the response rate (Hox & De Leeuw, 1994). Factors influencing high response rates include sending follow-up correspondence, providing prior notice of the study, the importance of the sponsor (e.g. governmental organisations and universities), including a stamped addressed envelope, personalisation of the cover letter, the salience and interest of the topic under research and the use of a cover letter were all shown to significantly increase response rates. This literature review provides useful information on the factors that increase study response rates to postal surveys and the factors reported above will be incorporated into this study.

2.4 Measures

Certain measures were chosen due to their previous use in relevant studies, whereas others were chosen due to their reliability, validity and familiarity with clinicians. Measures of burden and perceived social support were chosen to facilitate comparisons with previous studies, whereas measures of trauma, anxiety and depression were selected as they were familiar to clinicians and were reliable and valid. Based on clinical experience, these measures took less time to administer when compared with other commonly used assessments of PTSD, anxiety and depression.

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

The HADS is a widely used self-report measure developed for use in non-psychiatric settings. It has two subscales which measure symptoms of anxiety and depression. It has been used with a wide variety of populations, including primary care anxious and

depressed patients (Bjelland *et al.*, 2002; Runkewitz *et al.*, 2006), cancer patients (Myskakiidou *et al.*, 2005), panic disorder patients (Lowe *et al.*, 2003) and patients with PTSD (Evans *et al.*, 2003). The total score is commonly used as a single measure of emotional distress (Walker *et al.*, 2007).

In a review of 747 studies using the HADS, Bjelland *et al.* (2002) found that the anxiety subscale had a Cronbach's alpha for internal consistency that varied from .68 to .93 (mean .83). For the depression subscale the Cronbach's alpha varied from .67 to .90 (mean .82). They also reported that the most common factor structure was a two-factor model. Bjelland *et al.* concluded that the concurrent validity of the HADS with other widely used measures, such as the BDI-II and the GHQ, was 'good' to 'very good'.

Seven items measure anxiety and seven measure depression. The items are rated on a four point scale from zero to three and provide a maximum score of 21 for each of the two subscales, and a maximum total score of 42. Higher scores on the subscales and total score represent higher levels of distress. Participants are directed to rate their symptoms with respect to the preceding seven days. The HADS includes items such as 'I look forward with enjoyment to things' and 'worrying thoughts go through my mind'.

When interpreting the HADS, subscale scores from zero to seven are classed as 'normal', 8-10 'mild', 11-14 'moderate' and 15 and above 'severe'. (see appendix 9)

Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988)

The MSPSS is a self-report measure, which assesses perceived social support. It has been used in a number of clinical populations, such as patients with schizophrenia and major affective disorders (e.g. Cecil *et al.*, 1995), patients with cancer and depression (e.g. Hopco *et al.*, 2008) and patients with PTSD (e.g. Beck *et al.*, 2009; Haden *et al.*, 2007; Ozaltin *et al.*, 2004). The scale measures perceived social support from family, friends and a significant other. This MSPSS has good internal reliability (Cronbach's alpha .88 for total score) and also good test-retest reliability (.85). It has been shown to have high internal consistency in clinical samples (e.g. Cecil *et al.*, 1995). The MSPSS has good face validity and is negatively correlated with levels of anxiety and depression (Zimet *et al.*, 1988).

The MSPSS has 12 items and is divided into four questions for each of the three sources of support. It is scored on a seven point scale from one to seven, with a minimum score of 12 and a maximum score of 84. Higher scores indicate greater levels of perceived social support. The MSPSS includes items such as 'there is a special person around when I am in need' (see appendix 10).

Burden Inventory (BI; Zarit et al., 1980)

The BI is a self-report measure which assesses the extent to which caregivers feel that caregiving has affected their lives. It requires that caregivers answer questions relating to their experiences over the past 30 days. A three-factor structure has been confirmed, which measures patient's dependency, embarrassment/anger, and self-criticism (Knight *et al.*, 2000). This scale has good internal reliability (Cronbach's alpha .92 for total score) and good test-retest reliability (.71). The BI has good face

validity, although data are not provided for concurrent validity or predictive validity. The BI has been used with the carers of patients with a number of health problems, such as Parkinson's disease (e.g. Edwards & Scheetz, 2002), Alzheimer's disease (e.g. Knight *et al*, 2000) and PTSD (e.g. Manguno-Mire *et al.*, 2007).

The BI has 14 items and includes three questions on patients' dependency, nine questions on embarrassment/anger, and two questions on self-criticism. It is scored on a five point scale from zero to four and has a maximum score of 56. Higher scores suggest greater levels of burden. The BI includes items such as 'Do you feel strained when you are around your relative?' (see appendix 11).

When examining the items in the scale it can be seen that all of the items are negatively framed. This results in the questionnaire not being balanced; for example, a score of zero always indicates that the respondent does not have a difficulty with their relative and a score of four indicates that the respondent nearly always has a difficulty with their relative. The organisation of the questionnaire could lead the reader to a socially desirable response set, whereby they indicate that there is no problem and they circle zero on all items. In addition, if items were equally framed between positive and negative statements, then this would allow the assessor to see if the person was consistently agreeing with all of the items, which would be an indication that the respondent was not responding correctly to the questions (see Coolican, 2005).

Impact of Events Scale Revised (IES-R; Weiss & Marmar, 1997)

The IES-R is a widely used self-report measure of traumatic stress. It is highly correlated with a diagnosis of PTSD and scores of 33 and above are consistent with a diagnosis of PTSD (Creamer *et al.*, 2003). There are three subscales which measure intrusion, hyperarousal and avoidance. The IES-R has high internal consistency (Cronbach's alpha .96) (Creamer *et al.*, 2003) and has subscale test-retest scores of .51-.94 (Weiss & Marmar, 1997). This scale has high validity and has been used with non clinical samples (e.g. Shelvin & McGuigan, 2003) and in the assessment of treatment effectiveness (e.g. Cusack & Spates, 1999).

The IES-R contains 22 items, which include eight intrusion items, eight avoidance items and six hyperarousal items. Patients are asked to consider how they have been affected in the preceding seven days. The scale is scored on a five point scale from zero to four, with a maximum score of 88. Higher scores indicate greater levels of PTSD symptoms. The IES-R includes items such as 'any reminder brought back feelings about it' (see appendix 12).

Demographics Questionnaires

The current study used two questionnaires to collect demographic information from patients and significant others. Both questionnaires collected information on gender, relationship status, age and previous mental health problems. The significant others questionnaire also gathers information on the length of time that the respondent has known the patient and if there has been a change in the closeness of their relationship.

The patient questionnaire asks about the length of time since the trauma occurred, and also if there has been a change in the closeness in the relationship with the patient's significant other. Further information regarding the nature of the trauma was obtained through examination of the patient's psychology file. Patients agreed to this formally by ticking box number three on the consent form (see appendix 13).

2.5 Procedure

The study was conducted in two stages: 1) Patients were recruited through the assessment and treatment clinic. 2) A postal survey method was then used to contact the significant others of the patients.

Stage 1

Patients were identified and approached during their assessment or treatment appointments by therapists working in the trauma clinic. Following their assessment, patients were informed of the aims of the study by a therapist. Patients were provided with the information sheet and questionnaire at the end of the session and asked to take them home. If they decided to participate, they completed a demographics questionnaire and nominated a significant other from whom they received the greatest support. The questionnaire was then returned to the present author using the postage paid envelope provided. As part of the routine clinical assessment at the trauma centre, at the beginning of assessment sessions the IES-R was administered to all patients by therapists. The scores from IES-R were obtained from the therapist at a later date if the patient opted in.

Stage 2

On receipt of the patient's completed questionnaire, the present author contacted the significant other directly by post and provided detailed information regarding the aims of the study. Included was a covering letter and consent form (see appendix 14), the HADS, the BI and the MSPSS. If the significant other decided to take part, they completed and returned the questionnaires.

Demographic data were collected from patients and significant others (see appendixes 4 and 7). Patients and significant others were asked to participate once and no follow-up assessments were used. It was indicated that the time taken to complete the questionnaires would not exceed 20 minutes.

2.6 Inclusion Criteria

The following inclusion criteria were used:

1. Patient age between 18 and 65 years.
2. Patient having symptoms of PTSD, as measured by the IES-R.
3. Patient resident within the local NHS regional area.
4. Have a significant other or close friend.

Item one of the referral criteria was used as this was the population seen by the trauma centre. The other three criteria were not referral criteria, but were necessary for the current study. One significant other for each patient was included regardless of age and location of residence.

2.7 Power

Cohen (1992) suggested that the convention for levels of power for 'general use' is .80. Based on the results of previous studies, it was expected that correlations of about .40 between levels of significant other burden and levels of patient PTSD would be found. Cohen (1992) classified this as a medium effect size. To obtain a medium effect size at .80 power with a significance level of .05, the power tables provided by Clark-Carter (2004) indicated that when using a two-tailed Pearson correlation with an expected r of .4, 46 patients and their respective significant others would be required to achieve power levels of .80. However, it is also suggested that for non-parametric calculations, the number of participants should be multiplied by 1.1. This would therefore equate to 51 patients and their significant others being required to achieve power in the present study.

3.0 Results

3.1 Background Information

Results are provided for 25 patients and 25 significant others. Table 1 below describes the demographic characteristics of both groups. Data are also provided for the presence of previous treatment of psychiatric disorders.

Table 1: Demographic Characteristics, Relationship and Occupational Status and Previous Psychiatric Treatment for Patients and Significant Others

	Patients N=25 (%)	Significant Others N=25 (%)
Gender		
Male	14 (56)	6 (24)
Female	11 (44)	19 (76)
Relationship Status		
Single	4 (16)	4 (16)
In a Relationship	6 (24)	7 (28)
Married	14 (56)	13 (52)
Divorced	1 (4)	0
Separated	0	1 (4)
Occupational Status		
Employed	13 (52)	20 (80)
Unemployed	8 (32)	4 (16)
Retired	2 (8)	1 (4)
Undisclosed	2 (8)	0
Previous Treatment		
Depression	11 (44)	10 (40)
Anxiety	10 (40)	6 (24)
PTSD	5 (20)	0
Past Psychological Problems	2 (8)	3 (12)

It can be seen from the table above that five patients had previous treatment for PTSD and none of the significant others were treated. 10 patients reported receiving treatment for anxiety, whereas six significant others were treated for anxiety. It can also be seen that 11 patients had previously been treated for depression, whereas 10 significant others received treatment for depression.

3.2 Study Response Rates

Response rates will now be described for the two stages of data collection, which spanned an 18 month period. In the first stage, which involved the therapists recruiting patients from their caseload, 121 patients were provided with questionnaires. Of this sample, 42 patients returned completed measures. This provides a response rate of 34.7 per cent.

In the second stage, which involved the present author contacting the nominated significant others of the patients, 42 significant others were contacted. Of this sample, 28 significant others returned completed measures. This would give a response rate of 66.6 per cent for the second stage of data collection. Three completed sets of questionnaires were excluded as the patients' scores were below the cut-off for clinically significant levels of PTSD.

3.3 Missing Data

The following data were missing from the patient and significant others' questionnaires. Data were missing for one item on one BI questionnaire. A scale average for the missing item was substituted for the missing item. The missing item was on the embarrassment/anger factor and was replaced with the score of zero.

Patient age was missing for one participant but was not accounted for using procedures for the handling of missing data, as this would not have been appropriate given the nature of the data. Similarly, three patients reported an impact on the closeness of their relationships, but did not indicate whether the relationship had become closer or more distant. One significant other did not report that there had been

an impact on the closeness of her relationship. Therefore, percentages are based on the participants who completed their questionnaires in full, and no substitution procedures were used for demographic characteristics. Data were also missing for the type of trauma for six patients, as trauma type had not been written on the IES-R and it was not possible to access the files of these patients. The number of cases was therefore reported in Figure 1. Similarly, data were missing on occupational status for two patients and this was addressed by listing cases as undisclosed in Table 1.

3.4 Statistical Methodology

Examination of the data revealed that, with the exception of the Burden Inventory and the avoidance subscale of the IES-R, all other measures were not normally distributed. Therefore, non-parametric tests were used. However, where data were normally distributed, parametric tests were performed and compared with non-parametric tests. Data from the standardised assessments and demographics questionnaires were entered into SPSS version 15. Prior to analysis all variables were examined for accuracy of data entry and missing values. Non normally distributed data were analysed using Spearman's ρ correlations and normally distributed data were analysed using Pearson's r correlations.

3.5 Demographics

3.5.1 Patients

There were 25 patients in total (see Table 1). 14 of whom were male and the average age was 40.0 (S.D. 11.1). Patients all lived in Scotland and were assessed or treated for trauma by therapists. Patients' relationship status varied and although 80 per cent

were in some form of relationship, 20 per cent were single or divorced. Similarly, 80 per cent of patients lived with others, while 20 per cent lived alone. Patients reported experiencing a variety of traumatic experiences, such as combat exposure, road traffic accidents, aviation accidents and childhood sexual abuse (see Figure 1) and the average time since the trauma was 11.2 years, with a range from six months to 46 years. Of the 22 patients who reported a change in the closeness of their relationship with their significant other, 64 per cent indicated that their relationship had become more distant.

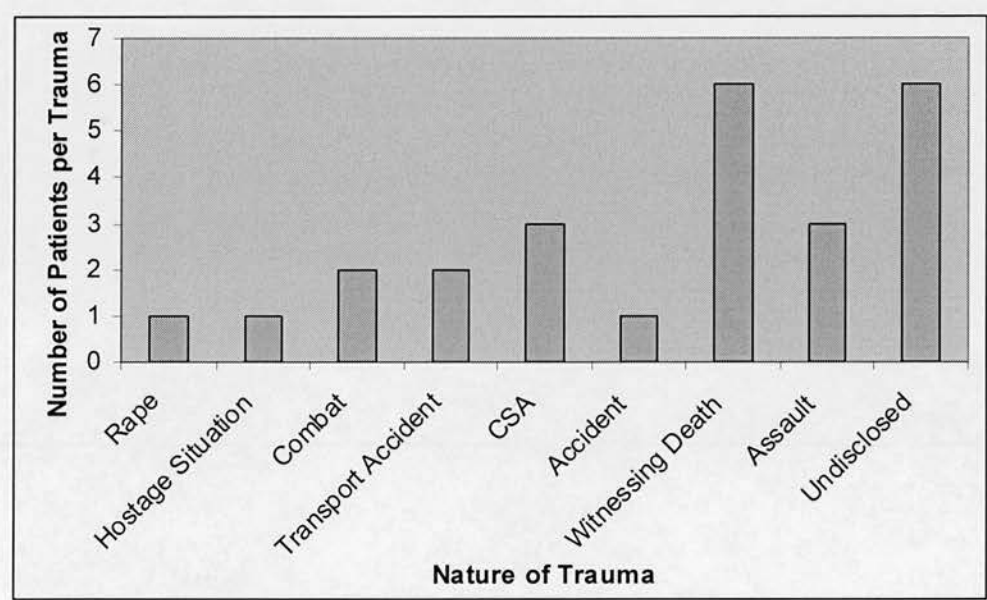


Figure 1: Numbers of Patients Reporting Each of Eight Categories of Traumatic Experiences.

The graph above shows that the most common cause of developing PTSD was witnessing the death of another person. Numbers of patients who did not disclose the nature of the trauma are also included. The variety of different traumatic precipitants shown above are not consistent with the previous literature, as previous studies have only focused on combat veterans.

3.5.2 Significant Others

There were 25 significant others in total (see Table 1), 19 of whom were female and the average age was 38.4 (S.D. 15.5). The inclusion of male significant others in the present study is different to the majority of previous studies, as they mainly assessed female significant others. Significant others all resided in the United Kingdom and had a close relationship with a person with PTSD. Also, 80 per cent of significant others were married or in a relationship and 64 per cent lived with patients and most (92 per cent) had daily contact. Significant others reported knowing the patients for an average of 18.5 years, with a range from 1 to 47 years. Of the 18 significant others who reported a change in the closeness of their relationship with the patient, 55.5 per cent reported that the relationship had become closer and 44.5 per cent reported that the relationship had become more distant. When asked if they received enough support, 36 per cent felt that they received enough support, whereas 64 per cent felt that they did not receive enough support.

When examining the results of the anxiety and depression scales of the HADS, it was found that 60 per cent obtained a score of at least 8, the cut-off for clinically significant levels of anxiety, and 48 per cent obtained a score of at least 8, the cut-off for clinically significant levels of depression. Furthermore, 40 per cent met the clinical cut-off for both anxiety and depression. In addition, it can be seen from the scores on Table 2 that the median score for anxiety in significant others was above the cut-off for clinical significance and the median score for depression was under, but close to, the level for clinical significance.

When comparing the results of the present study with those of previous studies, it can be seen that where descriptive statistics have been provided, the median score for levels of burden in the present study was lower than the average BI scores of 45.6 in the Manguno-Mire *et al.* (2007) study and 36.0 in the Calhoun *et al.* (2002) study. However, previous studies used different measures of PTSD and psychological distress, and therefore cannot be directly compared with the present study.

Table 2: Medians and Inter-quartile Range for Key Measures and Subscales for Patients and Significant Others

	Median	Inter-quartile Range
Patients (N=25)		
Intrusion	23.0	19.0 - 26.0
Avoidance	18.0	14.0 - 23.0
Hyperarousal	17.0	13.5 - 20.0
IES-R Total	59.0	50.0 - 66.5
Significant Others (N=25)		
HADS Anxiety	9.0	6.0 - 14.0
HADS Depression	6.0	3.5 - 10.5
HADS Total	18.0	9.0 - 22.0
MSPSS Total	43.0	29.5 - 64.0
BI Total	22.0	15.0 - 27.0

Table 3: Two-Tailed Spearman Correlations of Key Measures and Subscales for 25 Patients and Significant Others

	Intrusion	Avoidance	Hyper-Arousal	IES-R Total	HADS Anxiety	HADS Depression	HADS Total	MSPSS Total
HADS Anxiety	.17	.02	.16	.07				
HADS Depression	.13	.19	.12	.18				
HADS Total	.14	.08	.13	.09	.94			
MSPSS Total	.17	-.26	.09	-.04	-.08	-.33	-.21	
BI Total	-.01	.19	-.07	.04	.26	.35	.32	-.13

The correlation in each cell is Spearman’s rho. * $p<.05$ ** $p<.01$

3.6 Exploration of Hypotheses

All relationships were determined using two-tailed Spearman correlations at the 0.05 significance level.

Hypothesis 1: High Scores for Patients on the IES-R will be Associated with High Levels of Burden in Significant Others, as Measured on the BI

As can be seen from Table 3, no statistically significant correlations were found between the BI and the IES-R total score, or the BI and the IES-R subscales of intrusion, avoidance and hyperarousal. The correlation between the BI and the IES-R total was close to zero ($\rho=.04$, $N=25$, $p=0.84$). The correlation between the BI and the IES-R intrusion subscale was also close to zero ($\rho=-.01$, $N=25$, $p=0.92$). The correlation between the BI and the IES-R avoidance subscale was small ($\rho=.19$, $N=25$, $p=0.36$). The correlation between the BI and the hyperarousal subscale was negative and small ($\rho=-.07$, $N=25$, $p=0.72$).

Hypothesis 2: High Scores for Patients on the IES-R will be Associated with Greater Levels of Anxiety in Significant Others, as Measured by the HADS Anxiety Subscale (HADS-A)

For all comparisons there were no statistically significant correlations. The relationship between the IES-R total score and the HADS-A was small ($\rho=.07$, $N=25$, $p=0.73$). The relationship between the IES-R intrusion subscale and the HADS-A was small ($\rho=.17$, $N=25$, $p=0.39$). The correlation between the HADS-A and the IES-R avoidance subscale was close to zero ($\rho=.02$, $N=25$, $p=0.91$). The correlation between the HADS-A and the IES-R hyperarousal subscale was small ($\rho=.16$, $N=25$, $p=0.42$).

Hypothesis 3: High Scores for Patients on the IES-R will be Associated with Greater Levels of Depression in Significant Others, as Measured by the HADS Depression Subscale (HADS-D)

The correlation between the IES-R total and the HADS-D was small ($\rho=.18$, $N=25$, $p=0.38$). The correlation between the IES-R intrusion subscale and the HADS-D was also small ($\rho=.13$, $N=25$, $p=0.52$). Correlations between the HADS-D and the IES-R avoidance subscale ($\rho=.19$, $N=25$, $p=0.35$) and the HADS-D and the IES-R hyperarousal scale ($\rho=.12$, $N=25$, $p=0.56$) were both small. For all comparisons no statistically significant correlations were found.

Hypothesis 4: High Scores for Patients on the IES-R will be Associated with Greater Levels of Psychological Distress in Significant Others, as Measured by the Total Score on the HADS

The relationship between the IES-R and HADS total scores was small ($\rho=.09$, $N=25$, $p=0.65$). The relationships between the HADS total and the IES-R intrusion subscale

($\rho=.14$, $N=25$, $p=0.49$), the HADS total and IES-R avoidance subscale ($\rho=.08$, $N=25$, $p=0.70$) and the HADS total and the hyperarousal scale ($\rho=.13$, $N=25$, $p=0.52$) were all small. No statistically significant correlations were found.

Hypothesis 5: Increased BI Scores will be Associated with Increased Significant other Anxiety, as Measured by the HADS-A

The correlation between the BI and the HADS-A was medium ($\rho=.26$, $N=25$, $p=0.19$), although a statistically significant relationship was not found.

Hypothesis 6: Increased BI Scores will be Associated with Increased Significant Other Depression, as Measured by the HADS-D

The correlation between the BI and the HADS-D was medium ($\rho=.35$, $N=25$, $p=0.08$), although no statistically significant relationship was found. Post hoc power analysis revealed that the relationship was underpowered ($\beta=0.40$).

Hypothesis 7: Increased BI Scores will be Associated with Increased Significant Other Psychological Distress, as Measured by the HADS Total Score

The correlation between the BI and the HADS total score was medium ($\rho=.32$, $N=25$, $p=0.11$) and post hoc power analysis revealed that the relationship was underpowered ($\beta=0.34$). No statistically significant relationship was found between the BI and the HADS total score.

Hypothesis 8: Levels of Perceived Social Support by Significant Others, as Measured by the MSPSS will be Related to Significant Other Burden, as Measured by the BI

Lower scores on the MSPSS represent poorer social support. The correlation between the MSPSS and the BI was negative, small ($\rho = -.13$, $N = 25$, $p = 0.50$) and not statistically significant.

Hypothesis 9: Levels of Perceived Social Support by Significant Others, as Measured by the MSPSS will be Related to Anxiety, as Measured by the HADS-A

The correlation between the MSPSS and the HADS-A was negative, small ($\rho = -.08$, $N = 25$, $p = 0.69$) and not statistically significant.

Hypothesis 10: Levels of Perceived Social Support by Significant Others, as Measured by the MSPSS will be Related to Depression, as Measured by the HADS-D

The correlation between the MSPSS and the HADS-D was negative, small ($\rho = -.21$, $N = 25$, $p = 0.30$) and not statistically significant.

3.7 Additional Findings

The relationships between the length of time since the trauma and the subsequent impact on levels of burden have not been assessed previously in the literature. Using two-tailed Spearman correlations, it was found that these relationships were not significantly significant ($\rho = .26$, $N = 25$, $p = 0.20$), and the correlation was small. No statistically significant results were found for the time since the trauma and levels of

anxiety ($\rho=.16$, $N=25$, $p=0.42$), or the time since the trauma and depression ($\rho=.24$, $N=25$ $p=0.23$), with both correlations being small in magnitude.

3.8 Qualitative Information from Significant Others

In order to allow significant others to suggest if further support was necessary, and what form such support might take, a space was provided on the significant others questionnaire to allow them to write their opinions. What follows are the main types of interventions that were requested and quotes from specific questionnaires.

Negative Appraisals of Patient Care from the Perspective of the Significant Other

The partner of one patient wrote that she feels the medical profession requires a better understanding of PTSD, as her partner spent over five years being misdiagnosed. She also wrote that they had had to move over 300 miles to get specialist help and that a waiting list time of over twelve months was excessive.

Another patient wrote ‘I don’t know if you have ever seen a grown man cry because he is terrified of going to bed to sleep at night because of nightmares...watching him going through traumas like this every day rips my heart to pieces’.

Significant Others’ Opinions on Desired Support from the NHS

In terms of specific therapeutic help that could be provided, the following were suggested: support groups for the whole family including children and older adults; awareness of the impact of PTSD on the family; PTSD related information, which can be understood by family members of all ages; greater input from community

psychiatric nurses, and individual support for family members. One partner wrote 'just talking with someone who understands is helpful', and another wrote 'would welcome additional support from a therapist. Had one visit only with my husband present. Someone to discuss my feelings with'.

Another partner wrote 'some kind of therapeutic sessions to help explain the physical and symptomatic issues that have affected the patient and in turn affected my health, our marriage, lifestyle and home life. So much has been affected'. When examining the responses from the significant others, the most requested intervention was the provision of support groups.

4.0 Discussion

4.1 Overview

The discussion will begin with a summary of the key findings, followed by an examination of the hypotheses. Directions for future research will be discussed and the strengths and limitations of the study will be described. Implications of the current findings for the NHS will also be presented.

4.2 Summary of Key Findings

It was not possible to investigate fully the key research questions because of the small N . Based on previous research and the numbers of people assessed each year by the trauma centre, it was anticipated that a larger N would be achievable. However, although there are several possible reasons for this (to be discussed later), an important unanticipated finding was that based on anecdotal reports from therapists, many of those who have attended for the assessment and treatment of PTSD were unable to nominate significant others.

The key findings were that in relation to the hypotheses, there were no statistically significant associations. However, all correlations were underpowered. An important finding was that most of the significant others were experiencing clinically significant levels of anxiety, but this was not associated with levels of PTSD in patients. One cannot conclude that the levels of anxiety in the significant others are a consequence of having a close relationship with a person with PTSD. Even if an association had been found, a causal relationship could not have been assumed because many

significant others reported previous treatment for anxiety. This argument applies also to the relationships between PTSD and significant other depression.

4.3 Examination of Hypotheses

Caution should be exercised when considering the hypotheses in view of the limitations of the study which are outlined in section 4.9. Each research hypothesis will now be discussed.

4.3.1 Hypothesis 1: High Scores for Patients on the IES-R will be Associated with High Levels of Burden in Significant Others, as Measured on the BI

The above hypothesis was not supported as no statistically significant relationships were found between the BI, the IES-R total, or intrusion, avoidance and hyperarousal subscales. The correlations between all three components of the IES-R and the IES-R total scores in patients and levels of burden in significant others ranged from close to zero to small. In addition, as the avoidance subscale of the IES-R and the BI were normally distributed, Pearson's r correlations were also performed. However, even with the increased power of the parametric test, statistically significant associations were not found. For most of the comparisons, to achieve sufficient levels of power with such small correlations would require over 1000 participants (all estimations of power taken from Clark-Carter, 2004). In addition, such a small correlation would not be clinically important.

4.3.2 Comparisons of Current Findings with Previous Studies of Significant Other Burden and PTSD

The present study is the first to examine the relationships between levels of PTSD and significant other burden in the significant others of a non-combat exclusive population. When comparing the results of the present study with those reported in previous research, it is important to be aware that previous studies have used a range of different study designs and measures of PTSD and burden. However, three out of the four burden related studies reviewed used the BI. This was therefore used in this study to increase comparability with those studies.

When comparing the results of the current study with the results of previous studies (e.g. Beckham *et al.*, 1996; Ben Arzi *et al.*, 2000; Calhoun *et al.*, 2002; Dirkzwager *et al.*, 2005; Manguno-Mire *et al.*, 2007), they reported that PTSD total scores and levels of burden achieved effects ranging from small to large. However, the present study failed to support such findings, although this was most likely due to the small *N* and lack of statistical power. The current study used a correlational design, whereas Calhoun *et al.* used an independent groups design, reducing the extent to which they can be compared. A further limitation of previous studies was that only total scores on PTSD measures were used when assessing relationships with significant other burden. This limited the extent to which one could explain the particular aspect of PTSD which impacted most on burden in significant others. The present study, therefore, used a widely used measure of PTSD (the IES-R) and included the three subscales of intrusion, avoidance and hyperarousal to examine relationships between PTSD and burden.

It is also possible that the nature of trauma and the type of personal relationships that the patients had may have affected levels of PTSD and levels of burden in significant others. For example, all of the previous studies examined the effects of combat related PTSD on burden in significant others. It is therefore possible that the relationships reported in previous research are specific to this type of trauma. The current study included patients with a number of different trauma types and with differing levels of complexity (i.e. type I and II traumas). It is possible that the range of traumatic presentations had a differential impact on the current results. Furthermore, as combat related trauma is man made, repeated and prolonged, it is more closely associated with type II trauma (Herman, 2001). However, many of the participants in the present study experienced traumas that would be considered type I traumas. The inclusion of other types of relationships in the present study (i.e. friend or parent) may limit the extent to which the current study can be compared with other studies, as all of the previous work assessed female partners of combat veterans.

4.3.3 Hypothesis 2: High Scores for Patients on the IES-R will be Associated with Greater Levels of Anxiety in Significant Others, as Measured by the HADS Anxiety Subscale

The above hypothesis was not supported as statistically significant results were not found. The relationship between PTSD and significant other anxiety was determined by correlating the IES-R total score and subscales (e.g. intrusion, avoidance and hyperarousal) and the anxiety subscale of the HADS. The strongest association was between the intrusion subscale and the HADS-A. In order to achieve adequate power, over 600 participants would be required. When looking at the median score on the HADS-A, it can be seen that the score for significant others is 9, which is above the

cut-off for levels of clinical significance. In addition, the majority (i.e. 60 per cent) of the significant others of people with PTSD experienced anxiety. The prevalence of anxiety in the present study is higher than expected, as previous studies have shown prevalence rates for anxiety disorders in the general population, such as 1.6 per cent for generalised anxiety disorder (Kessler *et al.*, 1994), 6 per cent for agoraphobia (Reich, 1986) and 3 per cent for panic disorder (Reich, 1986). However, based on the current data set, it is not possible to determine the specific factors that are contributing to the levels of anxiety in significant others. It should also be noted that about a quarter of significant others reported that they had been previously treated for anxiety; therefore, their anxiety might be attributable to multiple factors.

4.3.4 Comparisons of Current Findings with Previous Studies of Significant Other Anxiety and PTSD

Only two previous studies have specifically assessed the relationships between total scores for PTSD in patients and anxiety in their significant others (e.g. Calhoun *et al.*, 2002; Westerink & Giarratano, 1999). Although the present study found no effect, Calhoun *et al.* (2002) and Westerink and Giarratano (1999) both found large effects. However, it is possible that the nature of the trauma may have had an impact on levels of anxiety in significant others, as although the present study included two combat veterans with PTSD, the majority of the sample were not combat veterans and it is therefore possible that the different causal experiences of trauma may affect patients in different ways, which could potentially lead to differing consequences for significant others. Herman (2001) suggests that personality changes are common following type II traumas. It is possible that the personality-based changes in patients may be an alternative contributory factor to levels of anxiety in significant others,

rather than levels of PTSD symptoms. However, this hypothesis cannot be answered using the present data and further studies would be required to examine the differences between types of traumas.

4.3.5 Hypothesis 3: High Scores for Patients on the IES-R will be Associated with Greater Levels of Depression in Significant Others, as Measured by the HADS Depression Subscale

The hypothesis above was not supported as the present results did not find any statistically significant relationships between the IES-R total score, its subscales and the HADS-D. However, to achieve sufficient power with the largest correlation, over 200 participants would be required. Furthermore, 40 per cent of significant others reported previous treatment for depression. Therefore, even if there had been a statistically significant correlation between levels of PTSD and levels of depression in significant others, it would not be appropriate to assume a causal relationship, as there could have been a number of other factors associated with the depression. In addition, it is possible that having a significant other with depression could exacerbate a patient's PTSD, although this cannot be concluded from the present data.

4.3.6 Comparisons of Current Findings with Previous Studies of Significant Other Depression and PTSD

The relationships between significant other depression and PTSD in patients have only been examined in one previous study (e.g. Calhoun *et al.*, 2002). Although the present study found a non statistically significant small effect, Calhoun *et al.* (2002) found a medium effect. Forty eight per cent of the significant others of people with PTSD in this study reported levels of depression that were above the cut-off for

clinical significance and clinicians may need to examine this when working with the significant others. Nevertheless, it cannot be concluded from the present data that there is a direct link between levels of PTSD in patients and levels of depression in their significant others. Unfortunately, Calhoun *et al.* did not provide data on the percentages of participants who experienced depression, and so it is not possible to compare the two studies in this respect.

4.3.7 Hypothesis 4: High Scores for Patients on the IES-R will be Associated with Greater Levels of Psychological Distress in Significant Others, as Measured by the Total Score on the HADS

The present study failed to find any statistically significant relationships between the IES-R total score and subscales, and the HADS total score. The comparisons were underpowered and in order to achieve statistical significance with the sizes of correlations in this study, about 800 participants would be required.

4.3.8 Comparisons of Current Findings with Previous Studies of PTSD and Significant Other Psychological distress

A number of studies have only used composite measures of anxiety and depression to represent a total score for psychological distress, obscuring the relative contribution of each emotional state. The present study also used a composite measure to enhance comparability. However, in previous studies, the relationships between significant other psychological distress and levels of PTSD in patients were significant (e.g. Beckham *et al.*, 1996; Ben Arzi *et al.*, 2000; Calhoun *et al.*, 2002; Dirkzwager *et al.*, 2005; Manguno-Mire *et al.*, 2007; Westerink & Giarratano, 1999).

The present study is the first to explore the relationships between PTSD subscales and their relationship with significant other anxiety and depression. Therefore, future studies may wish to replicate this approach, as having an increased understanding of the specific factors which contribute to significant other anxiety and depression may better inform clinicians regarding the particular symptoms which are most likely to impact on significant others, guiding treatment plans and family interventions.

4.3.9 Hypothesis 5: Increased BI Scores will be Associated with Increased Significant Other Anxiety, as Measured by the HADS-A

The above hypothesis was not supported, the association between the levels of burden and levels of anxiety in significant others being low and not significant. It is therefore possible that for the significant others in the present study, experiencing increased burden did not lead to increases in levels of anxiety. Also, experiencing higher levels of anxiety did not lead to increased levels of burden. However, in order to achieve statistical significance, about 150 participants would be required.

4.3.10 Comparisons of Current Findings with Previous Studies of Burden and Significant Other Anxiety

Only one previous study has examined the relationship between levels of burden and anxiety in significant others (Beckham *et al.*, 1996). Beckham *et al.* found a medium effect between levels of burden and levels of anxiety. Both the Beckham *et al.* study and the present study used correlational designs; however, both studies used different measures of anxiety, which limits comparability.

It is conceivable that factors other than anxiety, which have not been assessed in the current study, might explain the presence of increased levels of burden in the significant others. For example, in a review of fifteen studies of burden, Baronett (1999) found that living with the patient and patient's age were predictors of significant other burden. In addition, Cook *et al.* (1994) found that in the significant others of those with severe mental illness, poorer psychological adjustment, younger caregiver age and the duration of the patient's illness were all predictors of increased burden. With the exception of the relationship between duration of patient's illness and burden, the other factors were not assessed in the current study. It is therefore possible that these factors might account for levels of burden shown by significant others, although it is not possible to conclude this from the current data.

4.3.11 Hypothesis 6: Increased BI Scores will be Associated with Increased Significant Other Depression, as Measured by the HADS-D

The association between the levels of burden and levels of depression in significant others was low and not significant. However, in order to achieve statistical significance with the correlations above, about 65 participants would be required. As noted earlier, there may be a conceptual overlap between burden and depression; therefore, one might expect that the correlation between these factors would have been greater than .35.

4.3.12 Comparisons of Current Findings with Previous Studies of Burden and Significant Other Depression

There are no other studies specifically examining the relationships between levels of burden and depression in the significant others of those with PTSD; rather studies

have used composite measures of psychological distress. However, a study by Song *et al.* (1997) found that in the significant others of people with mental illness, depression was related to high levels of burden. It is not possible to compare the results of the current study with those of the Song *et al.* study, as the nature of mental illness is different to that of PTSD. Therefore, it would be difficult to determine which psychological disorder caused the most burden without a comparison study.

4.3.13 Hypothesis 7: Increased BI Scores will be Associated with Increased Significant Other Psychological Distress, as Measured by the HADS Total Score

The association between the levels of burden and levels of psychological distress in significant others was low and not significant. In order to achieve statistical significance, about 80 participants would be required.

4.3.14 Comparisons of Current Findings with Previous Studies of Significant Other Burden and Psychological Distress

The present study failed to find a statistically significant relationship between levels of psychological distress and significant other burden. However the results of the Manguno-Mire *et al.* study showed a large effect. In addition, although Ben Arzi *et al.* did not provide a total score for levels of burden, their comparisons between levels of psychological distress and their four burden subscales all achieved large effects. The correlation in the present study ($\rho=.32$) was somewhat weaker than those of Ben Arzi *et al.* ($r=.62$) and Manguno-Mire *et al.* ($\rho=.67$), but was in the same direction.

There are a number of differences between the present study and the Ben Arzi *et al.* and Manguno-Mire *et al.* studies. For example, Manguno-Mire *et al.* used the BSI,

which assesses depression, anxiety and somatic symptoms and Ben Arzi *et al.* used the SCL-90-R, which measures depression, anxiety, somatisation, obsessive compulsive problems, hostility, phobic anxiety, paranoid ideation and psychoticism. The present study used the HADS, which is a less general measure. It is therefore possible that participants may have responded differently on these measures, as they have different items measuring anxiety and depression.

4.3.15 Hypothesis 8: Levels of Perceived Social Support by Significant Others, as Measured by the MSPSS will be Related to Significant Other Burden, as Measured by the BI

The association between levels of social support and levels of burden was low and not significant. It is interesting to note that there was negative (albeit low) association between these two variables. Future research using a larger sample size should further examine this relationship. With such a small correlation, in order to achieve sufficient levels of power, about 380 participants would be required.

4.3.16 Comparisons of Current Findings with Previous Studies of Significant Other Burden and Social Support

As the present study was the first to examine the above relationships, it is not possible to compare the findings of the present study with those of previous PTSD related studies. However, in a study of the relationships between mental illness and burden in significant others, Song *et al.* (1997) found that the largest predictor of burden was poor social support. Due to the differences between mental illness and PTSD, it is not appropriate to make direct comparisons between the present study and that of Song *et al.*, Future studies may wish to compare levels of social support and burden across a

number of different psychological disorders, as this would enable clinicians to compare the relative impact of different psychological disorders on patients' significant others.

4.3.17 Hypothesis 9: Levels of Perceived Social Support by Significant Others, as Measured by the MSPSS will be Related to Anxiety, as Measured by the HADS-A

The association between levels of social support and levels of anxiety was near zero and not significant. Furthermore, in order to achieve statistical significance with the correlations above, about 800 participants would be required.

4.3.18 *Comparisons of Current Findings with Previous Studies of Social Support and Anxiety*

This was the first time that these variables have been reported in research focusing on the experiences of the significant others of people with PTSD; therefore it is not possible to compare the findings of the present study with those of previous work. However, Dean and Lin (1977) found that increased levels of social support acted as a buffer against anxiety and psychological distress. In addition, a study of caregiving in Scotland found that levels of social support were significantly associated with levels of anxiety, suggesting that those caregivers with less social support reported higher levels of anxiety (Phillips *et al.*, 2009). It might therefore be worthwhile re-examining these relationships using a larger sample.

4.3.19 Hypothesis 10: Levels of Perceived Social Support by Significant Others, as Measured by the MSPSS will be Related to Depression, as Measured by the HADS-D

The association between levels of social support and significant other depression are greater than those of social support and burden and social support and anxiety. However, the correlational relationship between depression and social support was low and not significant. Further research is required using a larger *N*, although given the strength of the present relationship, about 180 participants would be required.

4.3.20 Comparisons of Current Findings with Previous Studies of Social Support and Depression

As with the relationships between social support, anxiety and burden, there is a lack of previous PTSD related research with which to compare the present findings. However, Dirkzwager *et al.* (2005) examined the effects of vicarious trauma and psychological distress (e.g. sleeping and somatic problems and hyperarousal) in the significant others of combat veterans and found that these symptoms were significantly correlated with negative social support. However, Dirkzwager *et al.* did not assess the relationships between poor social support and anxiety or depression, so it is not possible to compare their study with the present study.

A review of the literature on the relationships between social support, anxiety and depression suggested that although social support can act as a buffer against distress, people who have good social support might still experience stress and depression (Vilhjalmsson, 1993). It is possible that a mediating variable such as increased burden could affect levels of anxiety and depression, which reduces the impact of social

support. However, this conclusion cannot be supported using the present data, as more sophisticated analyses would be required using a larger sample.

Differences in levels of burden and support between friends or family members would be an important topic to investigate. Unfortunately, the differences between types of relationships could not be assessed in the present study. However, Laffaye *et al.* (2008) reported that veterans perceived levels of social support to be higher from veteran friends compared with non-veteran friends. Furthermore, they perceived greater levels of social support from veteran friends than relatives. This is an interesting finding and although Laffaye *et al.* did not measure levels of burden or psychological distress in the significant others, it is possible that the people who provide social support may experience a negative consequence to their own wellbeing as a result of doing so.

4.4 Examination of Additional Findings

When reviewing previous research it became apparent that although studies referred to PTSD as ‘chronic’ (e.g. Calhoun *et al.*, 2002; Evans *et al.*, 2003), or assessed people from populations where the length of time since the trauma had been substantial, for example the Vietnam War (e.g. Beckham *et al.*, 1996; Calhoun *et al.*, 2002; Evans *et al.*, 2003; Westerink & Giarratano, 1999), the length of time since the trauma was not reported or assessed. The present study examined the relationship between the duration of time since the patients’ trauma and levels of burden on their significant others. It was found that these variables were not significantly correlated, the association being low. However, if future research found strong associations, it could suggest that the cognitions and behaviours, which are common in PTSD, might

become more entrenched with time and affect the way that people with PTSD interact with others. If so, it could suggest that people with more entrenched PTSD are more difficult to have a close relationship with, leading to an increase in the significant other's perception of burden. However, this investigation would require more sophisticated statistical tests, such as path analysis, as there are a number of other variables which could mediate the relationship between the duration of a person's PTSD and the levels of burden in their significant other.

The present study did not find significant relationships between the time since the trauma and levels of anxiety, and the time since the trauma and levels of depression, the associations between these variables being low and not significant. Although the length of time since the trauma was not measured in the Beckham *et al.* (1996) study, they compared levels of burden in the significant others of combat veterans with PTSD after eight months and found that levels of caregiver burden had increased significantly. However, this was a relatively short period and further research on time since trauma is needed.

A further interesting finding was that of the patients who reported a change in the closeness of their relationship with their significant other, over one third indicated that their relationship had become closer. This is surprising as Kaniasty and Norris (2008) suggest that people with PTSD are often likely to remove themselves from their social networks or behave in ways which could compromise their relationships. However, there is now a growing literature on the positive effects following trauma (post-traumatic growth) which may account for this. For example, Tedeschi *et al.* (1998) reported a number of positive consequences of post-traumatic growth, such as an

increased appreciation for life, closer intimate relationships and an increased sense of personal strength. However, a review by Zoellner and Mearcker (2006) concluded the evidence in support of post-traumatic growth was limited and the notion had a dubious theoretical basis.

Similarly, there were also positive changes in the relationship between significant other and patient, in that, of the significant others who reported a change, over half indicated that their relationship had become closer. This would go against what might be expected given the large number of studies linking a patient's PTSD to psychological distress in significant others (e.g. Beckham *et al.*, 1996; Dekel *et al.*, 2005; Lyons, 2001; Manguno-Mire, *et al.*, 2007; Westerink & Giarratano, 1999). However, although there is an absence of studies examining the positive aspects of supporting a person with PTSD, a number of studies have examined the positive effects of caring for people with other psychiatric problems. Positive experiences have included a sense of companionship and fulfilment (Cohen *et al.*, 2002), increased sense of satisfaction gained through being able to help one's relative and also increased feelings of love, hope and pride (Veltman *et al.*, 2002). The findings of Cohen *et al.* and Veltman *et al.* might go some way towards helping to understand why some significant others perceived an increase in the closeness in their relationships with the patient, although this cannot be concluded in the present study as positive aspects in relationships were not specifically examined.

4.5 Preliminary Analysis of Themes from Open-Ended Questions

Of those who responded, 64 per cent reported that they did not receive enough support from services. The main theme which emerged was that more input from

health services was required for significant others. More specifically, support groups were required for family members of all ages and mental health professionals, such as community psychiatric nurses and therapists, should be accessible. One person said 'just talking about it helps', but if there is a lack of services to facilitate support and discussion, then it is understandable that significant others would feel let down. The opinions of significant others might guide trauma services and remind therapists that significant others also require help. Furthermore, input could be provided in a group format, making the best use of limited resources.

Reports suggested that there was insufficient information available to significant others regarding the nature of PTSD and its impact on relationships. Services may therefore need to develop materials, so that significant others are aware of the potential impact to their relationship and to help them understand that PTSD can have both positive and negative consequences. Greater access to mental health professionals and PTSD related information for significant others, may go some way towards helping them to feel better supported and prepared.

The NICE (2005) guidelines suggest that healthcare professionals should be aware that PTSD can have an impact on the whole family and that many families require support. The guidelines state that families of those with PTSD should be fully informed about the common reactions to traumatic events; including PTSD related symptoms, likely course of treatment; and that families should be encouraged to attend self-help groups. Unfortunately, there is insufficient provision of self-help groups for people with PTSD or their significant others. Comments from significant others in the current study highlight gaps in service provision. It might be advisable

for trauma services to go beyond the standard one-to-one therapeutic approach and routinely involve significant others in the therapeutic process. Furthermore, services could benefit from developing easily accessible materials for children and adults, which explain the consequences of PTSD and its impact on the family, as these could help to increase the understanding of PTSD in significant others, which could increase empathy towards patients.

A number of significant others also reported their negative experiences. For example, one highlighted her distress saying 'I don't know if you have ever seen a grown man cry because he is terrified of going to bed to sleep at night because of nightmares...watching him going through traumas like this every day rips my heart to pieces'. This example highlights the negative emotional consequences that can be experienced by significant others and strengthens the need to ensure that significant others are supported by services. These experiences are consistent with those of some of the women interviewed in the qualitative studies by Lyons (2001) and Dekel *et al.* (2005). Both studies also found that the partners of combat veterans became heavily involved with their partner's illness and the wives themselves would often describe feeling stressed and depressed.

Another highlighted that she had experienced poor care from the health service, as her partner spent over five years being misdiagnosed and they had to move over 300 miles to access specialist help. If these experiences were found to be common, then this would mean that service providers were not meeting the needs of a large number people in the community and would therefore have to consider allocating resources towards the treatment of significant others. However, the findings of the responses to

open-ended questions are purely suggestive, but provide some pointers for following this up with qualitative research.

In terms of service provision, the comments above indicate that nationally there is inadequate services for people with PTSD and the additional stress caused to significant others by having to relocate over 300 miles is unlikely to help the patient with PTSD or their significant other. It may also be useful for trauma services to play a larger role in the training of other professionals, so that PTSD can be diagnosed more accurately.

4.6 Implications for the NHS

The results suggest that a number of the significant others of people with PTSD are experiencing clinically significant levels of anxiety (60 per cent) and depression (48 per cent). This has implications for how therapists treat people with PTSD, in terms of making additional efforts to ensure the care of significant others.

As part of the routine assessment process for people with PTSD, it may be useful for therapists to provide significant others with the Burden Inventory and a brief assessment of anxiety and depression, such as the HADS, so that they can have an understanding of the impact that patients are having on their significant others. Such routine collection of data may also be useful for further research into the relationships between these factors. In addition, therapists should involve significant others in the treatment process for those with PTSD, as this would enable significant others to have a better understanding of the nature of PTSD and their involvement could provide

additional help and support for the patient when working on trauma related difficulties out with treatment sessions (NICE, 2005).

There are also wider implications for the NHS, because if therapists treat the significant others of those with PTSD, this could place extra strain on already limited therapeutic resources. Nevertheless, it is important that there is access to care for those who need it and previous research and the present study have highlighted that significant others are a population who may require additional resources.

Currently there are no specialist support groups nationally for those with PTSD or their significant others. The creation of such groups may help to maximise the limited therapeutic resources available and may also further develop the current arrangements between NHS services and the voluntary sector. The NICE (2005) guidelines state that families and carers should be informed of local support groups and encouraged to attend where such groups exist.

Calhoun *et al.* (2002) suggested that treatment and psychoeducation programmes focused on methods of reducing burden, anxiety and depression may help significant others to be in a better position psychologically to support people with PTSD. However, further research on these methods is necessary, and as the majority of research in this area has been conducted on veteran samples, research using NHS patients and their significant others may prove useful.

It is also important to highlight that, according to therapists' accounts, a large proportion of patients did not have any significant others. This means that patients

could potentially feel less supported. However, the NHS could help to address this by facilitating access to befriender programmes and encouraging closer working between the NHS and voluntary agencies that support people with mental health difficulties.

4.7 Statistical Considerations

There are a number of important statistical considerations regarding the data in the present study. For example, as most data were skewed or not normally distributed and the N was small ($N=25$), it was decided that Spearman's ρ should be used. However, Coolican (2005) suggested that the use of non-parametric tests can sometimes result in the range of data being lost through the ranking process and that such tests are less sensitive for detecting significant relationships when compared with parametric tests.

About 120 patients are assessed each year by the Trauma Centre and it was anticipated that the refusal rate would be about 40 per cent (refusal rate based on the review of response rates to postal studies in Hox and De Leeuw, 1994). This was estimated to be adequate, as it was determined that recruiting 72 participants would be sufficient for a correlational study. However, if more people were recruited, then a more powerful analysis such as regression would have been used (see Dow *et al.*, 2007).

The present study used a large number of comparisons and it has been suggested that when multiple comparisons are made, correction procedures such as the Bonferroni procedure should be applied (Aron & Aron, 1999). However, it has been argued that adjustments are not necessary when performing multiple comparisons (Rothman,

1990). Due to the small N and lack of statistically significant correlations, this procedure was not employed.

If larger numbers of participants in both stages of the study had been recruited, levels of PTSD and other demographic variables between the patients who had significant others, and those who did not, would have been compared. This would have enabled an analysis of whether or not those with higher levels of PTSD were likely to have significant others who did not respond.

Furthermore, a larger N would have permitted comparisons on factors such as burden, anxiety and depression between partners, parents and close friends. These would have been useful comparisons, as Dirkzwager *et al.* (2005) found that mothers were more likely than fathers to experience psychological distress. Their study also suggested that females might be more likely than males to experience negative psychological consequences as a result of having a close relationship with someone with PTSD.

4.7.1 Effect Size

In order to avoid missing an effect that has been shown to be statistically non significant, Rosnow and Rosenthal (1988) suggested that effect sizes should be calculated for non-significant comparisons. They suggested that doing so would provide an indication of an effect in a particular condition and would highlight if larger samples should be used. They also note that small effects might be relevant. In the current study this was important, as the N was small and there was a lack of statistically significant results for all comparisons. However, the majority of the primary hypotheses showed associations which were either small or close to zero.

4.7.2 Post Hoc Power

Post hoc power is the retrospective power of an effect based on the sample size and the derived parameters of the data (Lenth, 2007). It has been suggested that power can be calculated retrospectively (Onwuegbuzie & Leech, 2004), although it has also been argued that power calculations performed after the data have been collected are not valid and should never be done (Lewis, 2000).

It has been suggested that post hoc power should be calculated particularly when non significant results are found. For example, if levels of power are high for a small effect, it is likely that the effect is truly a small effect. However, if levels of power are low, it is possible that the small effect could be statistically significant with higher levels of power (Lenth, 2007).

An important point to note is that although a study might be underpowered, there are instances when a study is so underpowered that it would require an unrealistic number of participants to achieve power and the effect might be so small that even though statistically significant, it might not be clinically meaningful. For example, with a correlation of .1, using the criteria used in the present study, about 600 participants would be required. However, a correlation so low would not be clinically meaningful and would require a very large, and potentially unachievable, sample size. With this in mind, it is important to strike a balance between reporting findings that are clinically meaningful and reporting all results that are underpowered. In the present study it was decided that post hoc power would only be reported where correlations were of .3 and above.

Within the present study, a point to note is that in relation to the hypotheses, no correlations were statistically significant. However, with an *N* of 25, two-tailed correlations would have needed to be at around .55 to be significant at the 0.05 level at the power of 0.80.

4.8 Strengths

The present study provides clinically rich and useful information regarding patients and their significant others who are seen by the local NHS clinical psychology services. At present this is an under-researched field of inquiry and little is known about the relationships between patients and their significant others. In addition, this study represents people with a wider range of traumatic experiences than reported in previous work and is therefore more representative of patients and their significant others who are treated in NHS settings. Furthermore, both male and female patients and significant others had broad age ranges.

This study contributes to the existing literature on PTSD and significant other/caregiver burden, as it is the first study to examine the effects of these factors in a non-combat mixed sample of NHS patients (see Figure 1 for range of different trauma precipitants). It is also the first study of its type to be conducted in the United Kingdom. The present study suggests a possible avenue for future research by widening the classification of significant others from partners (as is the focus of the previous research) to include other family members and close friends, who are currently unstudied populations.

The current study examined the individual subscales of the IES-R and how they related to burden and distress. This approach has not been utilised by any of the main studies of burden and psychological distress. Rather, previous research has relied on the use of a total score for PTSD. Adopting the current method could potentially identify the aspects of PTSD which are likely to be difficult for significant others to deal with. However, statistically significant relationships were not found using this approach.

A further strength of the present study was the use of the IES-R, which is a commonly used measure of PTSD in non combat veterans. A number of previous studies have used scales which were specifically developed to measure PTSD in combat veterans. The use of the IES-R allows future non combat related studies to draw comparisons with the present research.

4.9 Limitations

4.9.1 Slow Recruitment

From discussions with the trauma centre it was established that about 120 patients were assessed each year. However, after three months, only three completed sets of questionnaires had been returned. The current author went to great lengths in an attempt to recruit participants. For example, therapists were contacted on a regular basis to remind them to introduce the study to their patients. In addition, team meetings were attended and the slow progress was discussed. Consequently, it was decided that it may be beneficial to extend the recruitment sites. Ethical approval was sought and it was recommended that the study could be extended to become region-

wide and that data could also be collected in another NHS region. Clinical psychology departments throughout the regions were contacted and their team meetings were attended to promote the study. Reminder e-mails were also sent to the therapists. However, return rates from the new departments were also low. From discussions with therapists from the other clinical psychology departments, it was suggested that as there was a specialist trauma centre locally, other departments tended to refer on patients with PTSD.

The method of participant recruitment may have contributed to the low return rate. There were two main points of recruitment: the first when the therapist introduced the study to the patient and the second when the patient returned their questionnaire and nominated their significant other. One possible limitation of the first part was that therapists had to remember to introduce the study to their patients. Although efforts were made to remind therapists to do this, the therapist's primary concern is the assessment and treatment of their patient and the study may have often been forgotten at the end of a session. One possible future revision to this procedure, which could be tested by a comparison with the original method (i.e. the therapist introducing the study), would be for the researcher to directly contact the patient by telephone or post and then send a copy of the questionnaire and the IES-R, which could be completed and returned by the patient. This method would still permit patients to ask questions about the study when they met their therapist, or patients could contact the researcher directly. However, these approaches have a number of ethical limitations, which make them less desirable than the current approach. At the second point of recruitment, which involves the patient returning the name and address of their significant other, alternative procedures may be tested and compared.

It is also possible that the statement in the patient consent form (see appendix 13), which states that the author would have access to the patient's psychology file, might have increased the reluctance of some patients to participate in the study. It may be more appropriate in future studies to access information by asking questions directly on the patient questionnaire (e.g. nature of the trauma), as some patients may have declined to participate due to concerns about having an unknown person looking through their private history.

Hewison and Haines (2006) discuss a number of issues affecting participation rates in studies using NHS patients. For example, health research is likely to be novel to many patients who may not understand its scientific basis or the importance of a high response rate. Consequently, patients may decide that their input is not required. In addition, Hewison and Haines suggested that some patients may not respond, as they believe they are not a 'typical patient' or the topic is of no real importance to the NHS. However, discussions with the researcher can help to address these concerns. The present study attempted to tackle similar issues by providing detailed information leaflets and encouraging participants to ask questions.

4.9.2 Sample Size

It was estimated that 51 participants would be required to achieve adequate power (see section 2.7). The current study only recruited 25 participants, and so is underpowered. Following discussions with a number of therapists involved in the study, anecdotal evidence suggested that one of the main factors influencing the sample size was the lack of significant others among potential participants with

PTSD. For example, even though therapists explained the study to their patients, if patients did not have a significant other, then they would not return the questionnaire. A future study may request that patients complete the form and indicate that they have no significant others. A comparison of the IES-R scores between those with and without significant others could then be made.

Furthermore, as the main hypotheses of the study are that having a close relationship with a person with PTSD is likely to be associated with increased burden and psychological distress, if significant others are feeling burdened and distressed, they may view having to complete a number of questionnaires as an extra demand on their already overstretched resources. This issue warrants consideration in future studies. Furthermore, although efforts were made to select measures that were likely to cause minimum demands on significant others, future studies may wish to limit the number of measures used and aim to answer one or two specific hypotheses. This could further reduce the levels of effort that significant others would have to invest and may therefore increase participation. Such a design could be compared with the current design.

4.9.3 Generalisability

The current method of sampling is an issue, as although patients were sampled from a location with the highest likelihood of people with PTSD being present (e.g. the Trauma Centre), it is likely that there will also be people with PTSD who are either treated out with the NHS (e.g. by workplace therapists or private practice therapists) or have not yet requested treatment. This underscores the importance that the results

should be treated with caution when applied to other samples of people with PTSD and their significant others.

There are a number of further limitations, which include a self-selecting and non-randomly selected sample, which may not be representative of the wider population of people with PTSD. This limitation could be addressed to some extent by sampling a wider cross-section of the population, including those who are seen by workplace counsellors, clinicians in private practice and also by widening the sampling area to include other NHS localities across the UK. A multi-site study may help to address this limitation.

One of the most important limiting factors is the small N in the present study. A larger N would permit comparisons between gender, type of traumatic experience and other demographic variables. These comparisons would allow analysis of the homogeneity of the sample, which would in turn support the external validity of the study. Furthermore, although the response rate for the first stage of recruitment was acceptable (34.7 per cent), data were not available for the numbers of participants who decided not to participate due to the absence of significant others.

4.9.4 Design Considerations

An important limitation of the current design was the absence of reassessment and follow-up. A follow-up procedure would have allowed the participants to act as their own controls and would have provided data on the variability of burden and psychological distress over time. It is not possible to infer causal relationships from the current data. A longitudinal design might improve upon this and would be a useful

consideration for future studies. However, given the relatively small numbers of participants in the present study, sample attrition could pose a significant problem.

The current design was naturalistic in nature (i.e. recruiting patients with few exclusion criteria) and although the benefits of this type of approach have been highlighted above, when compared with the previous research, it is difficult to draw comparisons, as all of the previous studies focused on the wives of combat veterans, whereas the current study includes the significant others of patients with many different causes of PTSD. It is therefore possible that as the current sample is not homogeneous, the increased burden and psychological distress are a function of the type of PTSD (e.g. caused by rape, assault, RTAs or exposure to trauma in the line of duty), rather than the levels of symptoms on the IES-R.

This study relied on self-report measures; therefore it is possible that levels of burden or psychological distress might not be sufficiently expressed through completing a questionnaire. Alternative ways of understanding such information might be gained from behavioural observation or a qualitative methodology which focuses on the idiosyncratic experiences of the significant others of those with PTSD. Response rates for face-to-face interviews are higher; therefore this method may have provided larger numbers of participants than the questionnaire based method used by the current study. It is also possible that participants might not have been as motivated to complete the measures alone, as compared with face to face interviews where people feel more obliged to participate (e.g. Breakwell *et al.*, 2002).

The study only measured patients' PTSD. However, it is possible that patients had other comorbid conditions, such as depression, alcohol abuse or anger problems, which may have affected their significant others. For example, a review of the impact of PTSD on combat veterans' families noted that anger outbursts were common and a large proportion of the partners of those with PTSD had been physically assaulted (Galovski & Lyons, 2004). Furthermore, partner burden and psychological distress were highly correlated with the threat of violence from partners with PTSD (Calhoun *et al.*, 2002; Manguno-Mire *et al.*, 2007). In addition, when examining the relationships between perceived interpersonal functioning within the domains of close friendships, social life, romantic relationships and family relationships in those with PTSD, Beck *et al.* (2009) reported that levels of depression played a larger role in interpersonal strain when compared with PTSD alone. Moreover, poor family functioning in those with PTSD was significantly related to levels of depression (Evans *et al.*, 2003). Furthermore, partners' perceptions of poor family functioning were significantly correlated with levels of alcohol use in those with PTSD (Evans *et al.*, 2003). Future studies with larger sample sizes and methodologies which assess a wider array of clinical conditions may prove useful in determining the relative contribution of PTSD and its impact on significant others. In addition, qualitative studies might provide further insight into how other comorbid conditions, such as depression in people with PTSD, affect their significant others.

The aims of the present study required patients to have significant others. However, this is problematic, as it is possible that the significant others of the most distressed patients decided not to be associated with the patient as a consequence of being previously burdened and/or depressed through providing support. Certainly through

discussions with the therapists, this could be the case, as a number reported that their patients struggled to think of a person to nominate for the study.

One of the limitations of a cross-sectional study is the difficulty determining a person's premorbid functioning prior to them developing PTSD. It is, therefore, possible that the significant other might have felt burdened by the person before they developed PTSD and also received poor social support and experienced psychological distress prior to the patient becoming traumatised. The methods of addressing these limitations are often achieved using a prospective methodology, assessing a large number of people, and then following up those who later develop PTSD. However, this would not be possible in the current study, as a large proportion of the population of Lothian would have had to be assessed prior to the start of the study. Nevertheless, such studies are possible where the focus is on special groups, such as emergency service personnel and those in the armed forces who can be assessed before going on active service. It has been reported that people with psychological disorders are more likely to marry or live with others with psychological disorders (DuFort *et al*, 1994). Therefore, prospective studies would be required to assess if significant others had good mental health prior to the patient experiencing PTSD.

The present study is likely to have missed vulnerable groups, such as asylum seekers, who are known to experience higher levels of trauma than the general population (e.g. Ozer *et al.*, 2003), as there is another trauma service in Glasgow which treats this population. However, asylum seekers are a population who would be difficult to include in this study, as the measures are standardised with native English speakers. It is also possible that asylum seekers are less likely to have significant others in

comparison with the participants in the current study. This would be a fascinating area to explore in future work.

4.10 Interpretation of Findings and Future Research

Reports from therapists and the results of the present study suggest that patients with PTSD are a population who often lack significant others. In line with the results of Kaniasty and Norris (2008), there are two possible reasons account for this. Firstly a lack of significant others at the time of the patient's trauma may have led to an increased likelihood of the patient developing PTSD. Secondly, the ways in which people with PTSD often relate to those around them, and the increased likelihood that those with PTSD will isolate themselves from others, might then lead to social support networks retracting and significant others leaving. Anecdotal reports from clinicians support the second hypothesis. Future research may therefore attempt to contact significant others who are no longer part of the patient's support network, in an attempt to establish if these individuals are currently experiencing increased levels of burden, anxiety or depression.

It is important to discuss the possible reasons why there were a lack of statistically significant results in the present study, when compared with the existing research. There are a number of possible reasons for these differences; for example, previous studies assessed female partners of combat veterans, whereas the present study assessed male and female significant others. It is therefore possible that gender differences might account for the present findings. Furthermore, having a mixed sample of males and females might have also had an influence on the present results. It should also be noted that the lifestyles of the partners of combat veterans are likely

to be very different from those of civilian partners. For example, the partners of veterans live with the fear that their partner can be killed on active service and that each time they go on duty might be the last time they are seen. In addition, military families have to move residential location frequently, which can have an effect of social support networks and cause further stress. Families also have to deal with not seeing the veteran for months at a time. These factors are all stressful and are less likely for the partners of NHS patients.

A further possible explanation for the present results is the heterogeneity of the sample of significant others. For example, all of the veteran studies assessed wives, whereas the present study also assessed husbands, friends and other family members. This might have had an effect on the relationship between PTSD and significant other burden, as it is likely that wives will potentially spend more time, and have a greater dependence, than a friend or other family member. This dependence and proximity could therefore increase the time spent with a person with PTSD, which could then lead to greater levels of burden or psychological distress.

In terms of recruitment, a large number of the previous studies were completed with the help of veterans' associations. Often couples would be seeking treatment together, or specialist groups would be provided for veteran's wives. This is different to the present study, as a large number of patients did not have wives, or their wives were not receiving support. This difference may, in part, account for the differences in the results between the present and previous studies.

An alternative to the current recruitment procedure could be to send the pack of measures for the significant other to the patient at the start of the process. The patient could thereby nominate their significant other by giving them the pack of questionnaires containing a stamped addressed envelope. This process might reduce the time that each stage would take to complete. However, the limitation of the alternative procedure would be the absence of personalised introduction letters.

It may also be useful for a qualitative approach to be directed towards understanding the reasons why former significant others are no longer involved with those with PTSD. One further study, which would be helpful when interpreting the current results, would be to conduct a simple study of patients' social network sizes and compare this with a control group. Such a study might look at numbers of friends, family, or intimate relationships in people with PTSD in NHS samples.

The current study is particularly important for those considering conducting research with the significant others of NHS patients with PTSD, as it shows that despite considerable efforts to recruit from this population, small numbers of significant others limit the utility of a quantitative approach. Currently the only qualitative studies which examine the effect of PTSD on significant others are confined to studies of veterans' wives. The current research has found that as it is difficult to recruit the numbers of participants required using NHS patients, a qualitative approach may provide a further insight into how the partners and significant others of non-veterans are affected by PTSD.

It would be interesting to investigate the possibility that the significant others of those with type II traumas would experience greater levels of burden than those with type I. Future studies may wish to use this definition to compare the significant others of those from the two different categories of trauma. Other studies may also wish to compare the levels of significant other burden in PTSD to significant other burden in other anxiety disorders, such as panic and other phobic anxiety disorders, suggesting where help for significant others could be most usefully directed. Although there is currently a sizeable literature supporting the associations between having close relationships with people with Alzheimer's disease, schizophrenia, bipolar disorder and subsequent caregiver burden (e.g. Ohaeri, 2003), the research on burden in the significant others of people with anxiety disorders is limited (Kalra *et al.*, 2008).

Future research may also consider reassessing patients and their significant others following a time delay of one and two years. Reassessment would provide valuable information on whether those with high levels of PTSD are more likely to lose their significant others and would provide a greater understanding of how the relationship between PTSD, burden and psychological distress varies over time. As the present study was cross-sectional, less certainty can be placed on the consequences of these longitudinal relationships.

The majority of studies have used composite measures of psychological distress. However, this approach limits the extent to which anxiety and depression can be associated with burden in significant others. Therefore, measuring anxiety and depression separately might be a worthwhile approach for future studies investigating the factors associated with burden. Furthermore, using measures such as the SCL-90-

R, may aid in assessing the relationships between burden and the individual subtests. This would aid clinicians and researchers wishing to develop treatment provision for significant others, or to increase the psychological knowledge base regarding the relationships between burden and other psychological disorders.

Future studies might also wish to consider incorporating measures of posttraumatic growth. For example, using the present study design, if patients were given a measure of posttraumatic growth at the recruitment phase, then this could be used to establish if there were an association between levels of PTSD and levels of posttraumatic growth. In addition, it would be interesting to examine whether or not there is an association between perceived levels of posttraumatic growth in patients and corresponding associations with levels of burden and psychological distress in significant others. These are viable hypotheses for future research.

4.11 Conclusion

The present study was the first UK based study to examine the relationships between levels of PTSD in patients and the corresponding influence on levels of anxiety, depression, burden and social support in their significant others. An important finding in the present study was that clinicians suggested that many people with PTSD did not have significant others. This has important implications, as it has been shown in previous research that social support is one of the best protective factors against PTSD (Brewin *et al.*, 2000). However, the consequence of this finding has been that limited numbers of significant others have been available to participate in this study. The main results of the present study were all consistently negative and of low magnitude. Although previous studies reported a significant relationship between

levels of PTSD, psychological distress and burden in significant others, it has not been possible to replicate these findings, in part due to the small *N*. However, it is important to note that clinical levels of anxiety were reported in 60 per cent of significant others and clinical levels of depression were reported in 48 per cent of significant others. These figures are high and are above what would be expected in the general population. These findings will hopefully provide a step forward towards future investigations of the relationships between PTSD and levels of burden, anxiety and depression in the significant others of NHS patients.

5.0 References

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Appendix 1

Diagnostic Criteria for Posttraumatic Stress Disorder (DSM-IV-TR)

A. The person has been exposed to a traumatic event in which both of the following were present:

- (1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
- (2) the person's response involved intense fear, helplessness, or horror. Note: In children, this may be expressed instead by disorganised or agitated behaviour

B. The traumatic event is persistently reexperienced in one (or more) of the following ways:

- (1) recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions. Note: In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
- (2) recurrent distressing dreams of the event. Note: In children, there may be frightening dreams without recognisable content.
- (3) acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated). Note: In young children, trauma-specific reenactment may occur.
- (4) intense psychological distress at exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event
- (5) physiological reactivity on exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:

- (1) efforts to avoid thoughts, feelings, or conversations associated with the trauma
- (2) efforts to avoid activities, places, or people that arouse recollections of the trauma
- (3) inability to recall an important aspect of the trauma
- (4) markedly diminished interest or participation in significant activities
- (5) feeling of detachment or estrangement from others
- (6) restricted range of affect (e.g., unable to have loving feelings)
- (7) sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:

- (1) difficulty falling or staying asleep
- (2) irritability or outbursts of anger
- (3) difficulty concentrating
- (4) hypervigilance
- (5) exaggerated startle response

E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Specify if:

Acute: if duration of symptoms is less than 3 months

Chronic: if duration of symptoms is 3 months or more

Specify if:

With Delayed Onset: if onset of symptoms is at least 6 months after the stressor

Appendix 2

Diagnostic Criteria for Acute Stress Disorder (DSM-IV-TR)

A. The person has been exposed to a traumatic event in which both of the following were present:

- (1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
- (2) the person's response involved intense fear, helplessness, or horror

B. Either while experiencing or after experiencing the distressing event, the individual has three (or more) of the following dissociative symptoms:

- (1) a subjective sense of numbing, detachment, or absence of emotional responsiveness
- (2) a reduction in awareness of his or her surroundings (e.g., 'being in a daze')
- (3) derealisation
- (4) depersonalisation
- (5) dissociative amnesia (i.e., inability to recall an important aspect of the trauma)

C. The traumatic event is persistently reexperienced in at least one of the following ways: recurrent images, thoughts, dreams, illusions, flashback episodes, or a sense of reliving the experience; or distress on exposure to reminders of the traumatic event.

D. Marked avoidance of stimuli that arouse recollections of the trauma (e.g., thoughts, feelings, conversations, activities, places, people).

E. Marked symptoms of anxiety or increased arousal (e.g., difficulty sleeping, irritability, poor concentration, hypervigilance, exaggerated startle response, motor restlessness).

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or impairs the individual's ability to pursue some necessary task, such as obtaining necessary assistance or mobilising personal resources by telling family members about the traumatic experience.

G. The disturbance lasts for a minimum of 2 days and a maximum of 4 weeks and occurs within 4 weeks of the traumatic event.

H. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition, is not better accounted for by Brief Psychotic Disorder, and is not merely an exacerbation of a preexisting Axis I or Axis II disorder.

Appendix 3

Lothian NHS Board

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9009
www.nhslothian.scot.nhs.uk



Lothian Local Research Ethics Committee 03

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS

Telephone: 0131 536 9022
Facsimile: 0131 536 9346

26 June 2008

Mr Alan Grieve
Trainee Clinical Psychologist
Dept of Clinical Psychology
Royal Edinburgh Hospital
Morningside Terrace
Edinburgh
EH10 5HF



Dear Mr Alan Grieve*

Full title of study: A study of the relationships between post traumatic stress disorder, significant other burden and psychological distress.

REC reference number: 08/S1103/17

Thank you for your letter of 08 June 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information was considered at the meeting of the Sub-Committee of the REC held on 18 June 2008. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised and plus following points to be noted and supporting documents amended appropriately.

Points to note:-

- Consistent title of study needs to appear on all supporting documentation
- Both summary and full information sheets contain typos where indicated on attached copied sheets - please amend appropriately before issue
- Consent form for relatives or partners mentions information sheet dated 5th March 2008 v2 yet information sheet provided is dated 8th June 2008. Please amend appropriately before issue.

Ethical review of research sites



The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at sites requiring SSA.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		28 April 2008
Application	revised	
Investigator CV	CI	07 March 2008
Investigator CV		28 April 2008
Protocol	2	22 January 2007
Covering Letter		24 April 2008
Letter from Sponsor		
Compensation Arrangements		20 July 2007
Questionnaire: Patient	2	24 April 2008
Questionnaire: HADS		
Questionnaire: for Relatives and Partners	3	08 June 2008
Letter of invitation to participant	1	24 April 2008
Participant Information Sheet: Participant IS (Relative/Partner)		05 March 2008
Participant Information Sheet: for Relatives and Partners	3	08 June 2008
Participant Information Sheet: Summary PIS	1	08 June 2008
Participant Consent Form: PCF	3	08 June 2008
Participant Consent Form: Participant CF		24 April 2008
Response to Request for Further Information		08 June 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.


We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/S1103/17

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

 Chair

Email: joyce.clearie@lhb.scot.nhs.uk

Enclosures:

~~List of names and professions of members who were present at the meeting and those who submitted written comments [if final opinion was confirmed was given at a meeting]~~
 "After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL- AR2 for other studies]
 Site approval form

Copy to:

Ms Marise Bucukoglu
 Mr Alan Grieve, NHS Lothian
 [R&D office for NHS care organisation at lead site]

Lothian Local Research Ethics Committee 03

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	08/S1103/17	Issue number:	0	Date of issue:	26 June 2008
Chief Investigator:	Mr Alan Grieve				
Full title of study:	A study of the relationships between post traumatic stress disorder, significant other burden and psychological distress.				
This study was given a favourable ethical opinion by Lothian Local Research Ethics Committee 03 on 18 June 2008. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.					
Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes ⁽¹⁾
<p>Approved by the Chair on behalf of the REC:</p> <p><i>[Signature]</i> (Signature of Chair/Co-ordinator)</p> <p>(delete as applicable)</p> <p><i>[Signature]</i> (Name)</p>					

(1) The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.

Patient Information Sheet

A study of the experiences of people who have a close relationship with a person with post traumatic stress disorder

You are being invited to take part in a research project about post traumatic stress disorder (PTSD). Before you decide if you would like to take part, you will need to understand why the research is being done and what it would involve from you. I would be grateful if you could read the following information carefully. **Please take time to decide whether or not you wish to take part.**

What is the purpose of the study?

This study is interested in how a person's traumatic experiences can affect other people. It will look at the support, strain or low mood that your relative may be experiencing. Understanding this will help us to know if further help is needed by people with PTSD or those close to them.

Why have you been invited?

You have recently attended for assessment at the Edinburgh Traumatic Stress Centre, Royal Edinburgh Hospital. This is where this study is taking place. Each person assessed over the next 8 months will be invited to participate.

Do you have to take part?

You do not have to take part in this study if you don't want to. If you decide not to take part, this will not affect your treatment at the Edinburgh Traumatic Stress Centre in any way.

What will happen to you if you take part?

You will be asked to complete a questionnaire, which usually takes no more than ten minutes to do. The information that you provide will remain confidential and will be treated as confidential information.

What will you have to do?

You will also be asked to nominate a person close to you to whom we could send a further questionnaire to. This is all that you will be asked to do.

Why should you take part?

Although there may not be any benefit to you directly, it is hoped that the information gained through this study will help professionals to better understand how PTSD affects patients and others in their family. This may also help us in considering what support may be required for people with PTSD or those close to them.

What if there is a problem?

If you have a concern about any part of this study, you should phone and ask to speak to the researcher who will do his best to answer your questions (0131 537 6904).

What will happen to the information that you provide?

The information collected will only be used for this study. Only the main researcher will have access. Each person's information will be given a number and will not be identified by name. Only the main researcher will have access to the names associated with the number. These measures are taken very seriously to protect the identity of all patients. All information will be kept in a locked filing cabinet on NHS property.

What will happen to the results of the research study?

A summary of the study will be fed back to you directly by post. The summary will not include any identifying information. All patients will be anonymous.

Who is organising and funding the research?

The study is organised jointly between NHS Lothian and The University of Edinburgh, and will form part of the academic requirements for the main researcher's participation in the training for the Doctor of Clinical Psychology course (D.Clin.Psychol).

Who can you contact for further details?

If you would like more information about the research at any time, then please contact the main researcher, **Alan Grieve, NHS Lothian, on 0131 537 6904**. Or if you require impartial advice, a useful website is INVOLVE (<http://www.invo.org.uk/>), which promotes public involvement in the NHS.

Alan Grieve (Trainee Clinical Psychologist)

CHI Number:

Patient Questionnaire

Please answer the following questions as fully as you can. Your answers will be kept confidential.

Please tick the box that applies for each question.

Age: _____ Male ☐ Female ☐

Occupation: _____

Are you: Single ☐ In a relationship ☐ Married ☐ Divorced ☐ Separated ☐ Other ☐

Do you live alone? ☐ or with others? ☐

	Yes	No
Have you been treated for or had problems with depression in the past?	<input type="checkbox"/>	<input type="checkbox"/>

Have you been treated for or had problems with anxiety in the past?	<input type="checkbox"/>	<input type="checkbox"/>
---	--------------------------	--------------------------

Have you been treated for or had problems with post traumatic stress disorder in the past?	<input type="checkbox"/>	<input type="checkbox"/>
--	--------------------------	--------------------------

Have you been treated for or had problems with other psychological difficulties in the past?	<input type="checkbox"/>	<input type="checkbox"/>
--	--------------------------	--------------------------

How long has it been since the traumatic event(s) happened? _____ (In years)

Has your PTSD had an impact on your relationship? (This question is about the person that you feel that you can share your problems with and/or get support from).

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

If yes, has your relationship become closer? ☐ or more distant? ☐

Please turn over.

This research project is also interested in the opinions of the people who are close to, and support, people who have experienced trauma (This could be a close family member, such as a parent, grandparent, brother or sister, partner or close friend). It would be very much appreciated if you could nominate a relative or close friend that you feel gives you the most emotional support (The person that you turn to when you are feeling worried or down).

Please provide the following information:

The person's relationship to you. _____

The person's name. _____

The address where they can be contacted:

Thank you very much for taking the time to answer these questions. Please return this questionnaire in the prepaid envelope.

Information Sheet for Relatives, Partners or Close Friends

A study of the experiences of people who have a close relationship with a person with post traumatic stress disorder

You are being invited to take part in a research project about post traumatic stress disorder (PTSD). Before you decide if you would like to take part, you will need to understand why the research is being done and what it would involve from you. I would be grateful if you could read the following information carefully. **Please take time to decide whether or not you wish to take part.**

What is the purpose of the study?

This study is interested in how a person's traumatic experiences can affect other people. It will look at the support, strain or low mood that a patient's partner, relative or close friend may be experiencing. Understanding this will help us to know if further help is needed by people with PTSD or those close to them.

Why have you been invited?

I am interested in the opinions of people who have a close relationship with a patient who has PTSD. This can be a partner, close family member or close friend who is there to offer emotional support. Your relative/partner/friend recently nominated you as the person whom they felt that they could turn to for emotional support.

Do you have to take part?

As this is a postal survey you will not need to meet with me unless you want to. If you do not want to take part, you can simply disregard this letter and not complete the enclosed questionnaire. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care that you or the person close to you receives. Please take up to one week to decide if you would like to participate.

What will happen to you if you take part?

You will be asked to complete the enclosed questionnaire, which usually takes twenty minutes to complete. The information that you provide will remain confidential.

What will you have to do?

If you agree to take part you will be asked to complete a questionnaire. This asks about your age, the length of time you have known the patient and your relationship to them. You will also be asked about the social support that you receive, your mood and any possible strain that you might be under. After you have completed the questionnaire, you should use the postage paid addressed envelope and post it.

Why should you take part?

Although there may not be any benefit to you directly, it is hoped that the information gained through this study will help professionals to better understand how PTSD affects patients and others in their family. This may help us in considering what support may be required for people with PTSD or those close to them.

What will happen if you don't want to carry on with the study?

You can withdraw from the study at any time. If you wish to withdraw from the study, all of your information will be destroyed and will not be included in the final write up. Withdrawing from the study will not affect you or the person that you know who is receiving treatment from the NHS.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do his best to answer your questions (0131 537 6904).

Will your taking part in this study be kept confidential?

Your participation in the study will be kept confidential and all of the information that has been collected from you will not be identifiable.

What will happen to the information that you provide?

The data collected will only be used for this study. Only the main researcher will have access to the questionnaires. Each person's data will be allocated a number and will not be identified by name. Only the main researcher will have access to the names associated with the specific number. These measures are taken very seriously to protect the anonymity of all participants. All information will be kept within a locked filing cabinet in NHS property. The information that you provide will **not** be shown to your relative/partner/friend at any time.

What will happen to the results of the research study?

A summary of the study will be fed back to you directly by post. The summary will not include any identifying information. All participants will be anonymous.

Who is organising and funding the research?

The study is organised jointly between NHS Lothian and The University of Edinburgh, and will form part of the academic requirements for the main researcher's participation in the training for the Doctor of Clinical Psychology course (D.Clin.Psychol).

Who can you contact for further details?

If you would like more information about the research at any time, then please contact the main researcher, **Alan Grieve, NHS Lothian, on 0131 537 6904.**

Alan Grieve (Trainee Clinical Psychologist)

Appendix 7

Dept of Clinical Psychology
Royal Edinburgh Hospital
Morningside Terrace
Edinburgh EH10 5HF
Telephone 0131 537 6004
Fax 0131 537 6930



A study of the experiences of people who have a close relationship with a person with post traumatic stress disorder

Dear

I am writing to ask if you would like to consider taking part in my study. Recently (name of patient) attended for assessment at an NHS Clinical Psychology Department. During the assessment you were nominated as the person whom your relative felt that they could turn to if they were in need of support.

I am interested in the views of people who have a close personal relationship with a person who has experienced trauma. I have enclosed a questionnaire which asks questions concerning if you yourself feel supported and if you are experiencing strain or low mood.

I would be most grateful if you would consider completing the enclosed questionnaires, as this study will help our service to better understand if further services are required for the relatives of people with post traumatic stress disorder. It will also help us to understand the experiences of people who have a close relationship with a person who has experienced a traumatic event. This research also forms part of my assessment for my qualification for the Doctor of Clinical Psychology course at the University of Edinburgh.

The information that you provide is completely confidential and the enclosed questionnaire should only take up to twenty minutes to complete. I have enclosed a stamped addressed envelope. You are under no obligation to take part in the study, and not wishing to take part will not affect the care that you or your relative receives from the NHS.

I have enclosed an information leaflet, which provides further details about confidentiality and participation in the study. **Please return within the next seven days.**

Thank you very much for taking the time to read this letter.

Yours sincerely

Alan Grieve
Trainee Clinical Psychologist

Questionnaire for Relatives, Partners and Close Friends

Please answer the following questions as fully as you can. Your answers will be kept confidential.

Please tick the box that applies for each question.

Age: Male ☐ Female ☐

Occupation: _____

Are you:

Single ☐ In a relationship ☐ Married ☐ Divorced ☐ Separated ☐ Other ☐

What is your relationship to the patient?

How many years have you known the patient? _____ (In years)

Do you live with the patient? Yes ☐ No ☐

How often do you usually have contact with your friend or relative?

Daily ☐ Weekly ☐ Fortnightly ☐ Monthly ☐ Occasionally ☐ Never ☐

Have you been treated for or had problems with depression in the past? Yes ☐ No ☐

Have you been treated for or had problems with anxiety in the past? ☐ ☐

Have you been treated for or had problems with post traumatic stress disorder in the past? ☐ ☐

Have you been treated for or had problems with other psychological difficulties in the past? ☐ ☐

Has there been any change in the closeness of your relationship since the trauma?

Yes ☐ No ☐

If yes, has your relationship become closer? ☐ or more distant? ☐

Please turn over

CHI Number:

Appendix 8

Do you feel that you receive the social support that you need? Yes No
☐ ☐

What additional social or practical support do you think mental health services could provide? (e.g. support groups, community psychiatric nurses, therapy sessions, etc).

Thank you for taking the time to complete this questionnaire.

Hospital Anxiety and Depression Scale (HADS)

 **GL**
assessment
the measure of potential

Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

A		D					A		D	
				I feel tense or 'wound up'		I feel as if I am slowed down				
3				Most of the time		Nearly all the time		3		
2				A lot of the time		Very often		2		
1				From time to time, occasionally		Sometimes		1		
0				Not at all		Not at all		0		
				I still enjoy the things I used to enjoy		I get a sort of frightened feeling like 'butterflies' in the stomach				
0				Definitely as much		Not at all		0		
1				Not quite so much		Occasionally		1		
2				Only a little		Quite often		2		
3				Hardly at all		Very often		3		
				I get a sort of frightened feeling as if something awful is about to happen		I have lost interest in my appearance				
3				Very definitely and quite badly		Definitely		3		
2				Yes, but not too badly		I don't take as much care as I should		2		
1				A little, but it doesn't worry me		I may not take quite as much care		1		
0				Not at all		I take just as much care as ever		0		
				I can laugh and see the funny side of things		I feel restless as if I have to be on the move				
0				As much as I always could		Very much indeed		3		
1				Not quite so much now		Quite a lot		2		
2				Definitely not so much now		Not very much		1		
3				Not at all		Not at all		0		
				Worrying thoughts go through my mind		I look forward with enjoyment to things				
				A great deal of the time		As much as I ever did		0		
				A lot of the time		Rather less than I used to		1		
				Not too often		Definitely less than I used to		2		
				Very little		Hardly at all		3		
				I feel cheerful		I get sudden feelings of panic				
3				Never		Very often indeed		3		
2				Not often		Quite often		2		
1				Sometimes		Not very often		1		
0				Most of the time		Not at all		0		
				I can sit at ease and feel relaxed		I can enjoy a good book or radio or television programme				
				Definitely		Often		0		
				Usually		Sometimes		1		
				Not often		Not often		2		
				Not at all		Very seldom		3		

Now check that you have answered all the questions

TOTAL

A	D

Appendix 10

Social Support

For each question, please circle the number which corresponds to how much you agree or disagree with the statement. For example, if you very strongly disagree with a statement circle 1. If you very strongly agree with a statement circle 7. If you neither strongly agree nor disagree circle 4.

1. There is a special person around when I am in need.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
2. There is a special person with whom I can share my joys and sorrows.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
3. My family really tries to help me.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
4. I get the emotional help and support I need from my family.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
5. I have a special person who is a real source of comfort to me.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
6. My friends really try to help me.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
7. I can count on my friends when things go wrong.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
8. I can talk about my problems with my family.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
9. I have friends with whom I can share my joys and sorrows.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
10. There is a special person in my life who cares about my feelings.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
11. My family is willing to help me make decisions.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree
12. I can talk about my problems with my friends.	Very Strongly Disagree	1 2 3 4 5 6 7	Very Strongly Agree

Appendix 11

BI

The following questions relate to how you have been feeling over the past 30 days. For each question, please circle the number which corresponds to how much you agree or disagree with the statement. For example, if you feel the statement never applies to you circle 0. If the statement applies rarely circle 1. If the statement applies sometimes circle 2. If the statement applies quite frequently circle 3. If the statement nearly always applies circle 4.

1. Do you feel you do not have enough time for yourself?	Never	0	1	2	3	4	Nearly Always
2. Do you feel embarrassed over your relative's behaviour?	Never	0	1	2	3	4	Nearly Always
3. Do you feel angry when you are around your relative?	Never	0	1	2	3	4	Nearly Always
4. Do you feel your relative affects your relationship with other family members in a negative way?	Never	0	1	2	3	4	Nearly Always
5. Do you feel your relative is dependant on you?	Never	0	1	2	3	4	Nearly Always
6. Do you feel strained when you are around your relative?	Never	0	1	2	3	4	Nearly Always
7. Do you feel your health has suffered because of your relative?	Never	0	1	2	3	4	Nearly Always
8. Do you feel that you do not have as much privacy as you would like, because of your relative?	Never	0	1	2	3	4	Nearly Always
9. Do you feel that your social life has suffered due to caring for your relative?	Never	0	1	2	3	4	Nearly Always
10. Do you feel uncomfortable about having friends over?	Never	0	1	2	3	4	Nearly Always
11. Do you feel your relative expects you to care for him/her, as if you were the only one he/she could depend on?	Never	0	1	2	3	4	Nearly Always
12. Do you wish you could leave the care of your relative to someone else?	Never	0	1	2	3	4	Nearly Always
13. Do you feel you should be doing more for your relative?	Never	0	1	2	3	4	Nearly Always
14. Do you feel you could be doing a better job in caring for your relative?	Never	0	1	2	3	4	Nearly Always

Appendix 12

CHI Number: _____

Impact of Event Scale – Revised

Below is a list of difficulties people sometimes have after stressful life events. Please read each item and then indicate how distressing each difficulty has been for you. DURING THE PAST SEVEN DAYS with respect to _____, how much were you distressed or bothered by these difficulties?

		Not at all	A little bit	Moderately	Quite a bit	Extremely
1	Any reminder brought back feelings about it	0	1	2	3	4
2	I had trouble staying asleep	0	1	2	3	4
3	Other things kept making me think about it	0	1	2	3	4
4	I felt irritable and angry	0	1	2	3	4
5	I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
6	I thought about it when I did not mean to	0	1	2	3	4
7	I felt as if it had not happened or was not real	0	1	2	3	4
8	I stayed away from reminders about it	0	1	2	3	4
9	Pictures about it popped into my mind	0	1	2	3	4
10	I was jumpy and easily startled	0	1	2	3	4
11	I tried not to think about it	0	1	2	3	4
12	I was aware that I still had a lot of feelings about it, but I did not deal with them	0	1	2	3	4
13	My feelings about it were kind of numb	0	1	2	3	4
14	I found myself acting or feeling as though I was back at that time	0	1	2	3	4

15	I had trouble falling asleep	0	1	2	3	4
16	I had waves of strong feelings about it	0	1	2	3	4
17	I tried to remove it from my memory	0	1	2	3	4
18	I had trouble concentrating	0	1	2	3	4
19	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea or a pounding heart	0	1	2	3	4
20	I had dreams about it	0	1	2	3	4
21	I felt watchful or on-guard	0	1	2	3	4
22	I tried not to talk about it	0	1	2	3	4

Appendix 13

Dept of Clinical Psychology
Royal Edinburgh Hospital
Morningside Terrace
Edinburgh EH10 5HF
Telephone 0131 537 6004
Fax 0131 537 6930



24th April 2008

Centre: Royal Edinburgh Hospital

Participant Identification Number for this study:

PARTICIPANT CONSENT FORM

Title of Project: **A study of the experiences of people who have a close relationship with a person with post traumatic stress disorder**

Name of Researcher: Alan Grieve

Please tick the box following each statement if you agree.

1. I confirm that I have read and understand the information sheet dated 5th March 2008 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that relevant sections of my clinical psychology notes and data collected during the study may be looked at by Alan Grieve and clinicians from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐

4. I agree to take part in the above study.

☐

Name of Participant Date Signature

Alan Grieve

Name of Person taking consent Date Signature

Appendix 14

Dept of Clinical Psychology
Royal Edinburgh Hospital
Morningside Terrace
Edinburgh EH10 5HF
Telephone 0131 537 6004
Fax 0131 537 6930



8th June 2008

Centre: Royal Edinburgh Hospital

Participant Identification Number for this study:

CONSENT FORM FOR RELATIVES AND PARTNERS

Title of Project: **A study of the experiences of people who have a close relationship with a person with post traumatic stress disorder**

Name of Researcher: Alan Grieve

Please tick the box following each statement if you agree.

1. I confirm that I have read and understand the information sheet dated 8th June 2008 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree to take part in the above study.

☐

Name of Participant Date Signature

Alan Grieve

Name of Person taking consent Date Signature